HUSSMAN INSTITUTE FOR AUTISM

Presume Competence

A guide to successful, evidence-based principles for supporting and engaging individuals with autism

- ***Presume Competence***
- ***Follow the Lead***
- ***Make Communication the Centerpiece***
- ***Offer Positive Behavior Support***
- ***Include and Adapt***
- ***Accommodate Sensory and Movement Differences***
- ***Build Relationships***
- ***Support Autonomy***

John P. Hussman, Ph.D.

Dr. Hussman is the Executive Director of the Hussman Institute for Autism, and the parent of a young adult with autism.

Please visit the Hussman Institute for Autism website http://www.hussmanautism.org for periodic updates to this manual.
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Introduction

"There is nothing in a caterpillar that tells you it's going to be a butterfly." - *Buckminster Fuller*

"And now here is my secret, a very simple secret. It is only with the heart that one can see rightly. What is essential is invisible to the eye." - *Antoine de Saint Exupery, The Little Prince*

The goal of this manual is to help you to improve the world of a person with autism. You don't need to become a professional therapist to help. It is enough to remain a parent, teacher, aide, caregiver, or interested friend.

What you will need is the awareness and patience to embrace people with autism as *different, not less*; the willingness to presume that people with autism are competent – even if evidence may be not be available at first; and the understanding that behavior is not random, but is instead motivated by necessity, frustration, sensory differences, or the need to communicate a request or thought.

People with autism may experience the world in ways that are unfamiliar to us, but they need us to remember that what we see on the outside may not be an accurate reflection of what exists within. The ability to communicate or regulate social interaction should not be confused with the ability to think or the capacity to love. Rather than labeling individuals as "low functioning" or "high functioning," we should recognize that people with autism vary in their *ability to demonstrate* competence. Our responsibility is then to presume, find, and strengthen that competence.

Just because a child may not be able to speak doesn't mean that he has nothing to say. Just because a person may be overwhelmed in social situations doesn't mean that she doesn't long for friendship. Just because someone has difficulty initiating movement doesn't mean he doesn't want to participate.

"We are just like you, with the same desires, and just need help to become a typical member of society." – Sue Rubin

The approaches that follow reflect a broad range of clinical research and evidence-based practices in autism. They are tied together by an indispensable set of principles: the presumption that people with autism have competence, the insight that they deserve to be treated as equals, the recognition that behavior reflects needs and communication, and the understanding that following a person's lead – whether a child or an adult – is the best way to capture their interest and motivation.

Many of these approaches can (and have) been elaborated in books and academic journals. We are particularly grateful to Robert and Lynn Koegel, Anne Donnellan, V. Mark Durand, and Stanley Greenspan, whose contributions to evidence-based practices begin with the recognition that people with autism are people first. We also thank educators including Paula Kluth, Doug Biklen, and Christy Ashby, and self-advocates including Jamie Burke, Sue Rubin, Naoki Higashida, Tito Mukhopadhyay, and Temple Grandin for their insights into inclusion, communication, and competence of those with autism.

The goal of this manual is to collect the essential components into a practical, comprehensive set of practices – so that families, teachers, and friends can *engage* people with autism within the activities of daily life at home, in school, and in the community.

By learning to truly engage people with autism, you can help them to develop better communication, learn and achieve, find ways to meet their needs without resorting to difficult behaviors, and develop genuine friendships.

Why Engagement Is Important

Autism is a condition that is defined and diagnosed by its symptoms, which include marked differences in social communication and social interaction, coupled with differences in behavior that may include repetitive, restricted, or very habitual patterns of action. Among the earliest differences observed in autism is a reduced level of engagement and "joint attention."[1] Typically-developing children tend to respond to their name, exchange smiles during social interaction, and actively share attention with their parents, focusing on various objects or events ("Look!") to draw others into a mutual interaction. Differences in joint attention and social orienting have been found to strongly distinguish young children with autism from their typically-developing peers.[2]

Much of the learning, language, social, and play skills of a young child develop in the context of back-and-forth interactions with parents and other caregivers. When a child with autism doesn't initiate or respond to attempts at joint interaction, the number of back-and-forth learning opportunities can fall substantially. Without the smiles, hugs, and excitement that typically reward parents for initiating play, language games, and other activities, the child with autism can experience fewer chances to learn.

Sometimes the movements of a child with autism may be slow or delayed, and attempts to speak may be difficult to understand. When this happens, it's natural for parents and caregivers to respond by meeting the child's needs without any expectation of words or other effort on their part. Children with autism are often overwhelmed by social interaction or the expectations of others, so it can also feel as if we are respecting their preferences by disengaging from them.

Koegel and Koegel suggest that children with autism can develop a sort of "learned helplessness" as the relationship weakens between the child's own actions and the outcomes in the child's world.[3] A key goal of intervention is to restore circles of positive, reinforcing, back-and-forth interaction that are so central to development. People with autism do need to regulate their world by having periodic breaks from input and demands, but these needs should be balanced by regular, structured, and positive interaction.

Because learning, language, and friendship are all dependent on repeated social interaction, structured, positive engagement is critical for a person with autism.

The good news is that research has taught us a great deal about how to engage adults and children with autism in a way that can significantly improve their lives. If you're a parent, most – but not all – of the parenting skills needed for a child with autism are the same as those for a typical child. If you're a teacher, most of the teaching skills needed for a student with autism are also the same as those for a typical student.



The main difference is that autism requires parents, teachers, and friends to be more deliberate in finding and creating rewarding opportunities for engagement, more systematic about those interactions, and more attentive to how those with autism may be experiencing the world even if they aren't able to tell us. Autism also requires us to hold up our end of the conversation; our part of the bargain; our willingness to initiate meaningful and reinforcing interactions – even when the person with autism may not be able to hold up his.

Always, we need to recognize that autism changes the way a person experiences the world. Activities, sounds, and interactions that seem perfectly comfortable for a neurotypical person may be overwhelming for a person with autism. Activities that we find uninteresting may be the source of great motivation, and these are important because they can provide a gateway to that person's world. One can support people with autism well by reading their cues to understand what is overwhelming and frustrating, and by following their lead to discover what is interesting and enjoyable.

A Comprehensive Approach

Autism is a "spectrum" condition that features marked differences in social communication and behavior, but those differences vary significantly across individuals. Some individuals with autism have great difficulty communicating, and trouble translating their intentions into action, and may have interests or routines that seem very restricted or repetitive (these traits are common in classic "Kanner-type" autism as it was originally described in 1943). Others on the spectrum may be highly verbal, with particularly extensive knowledge and expertise in certain preferred topics, but may find social communication and relationships difficult to navigate (these traits are common in "Asperger Syndrome," which was later included under the umbrella of "autism spectrum" conditions).

This handbook offers a practical, comprehensive set of evidence-based practices that we view as essential in understanding and supporting individuals with autism. Because the autism spectrum is so broad, not every individual will require these components to the same degree. Still, because autism affects so many areas like communication, behavior, social interaction, and sensory experience, none of them should be ignored.

Teaching approaches are often pursued without adequate sensory accommodation or positive behavioral support. Social "skills" may also be pursued outside of any context that might lead to genuine social relationships. Too often, the objective of intervention is to "manage behavior" of people with autism without treating them as equal persons or seeking to improve their communication, relationships, engagement, or quality of life. All of us would be frustrated if the natural operation of our brains and bodies had the consequence of excluding us from friendship, limiting our opportunities for meaningful engagement with others, or preventing us from expressing our thoughts and needs.

It's important to consider all of these needs. Think of the following components as interlocking parts of an effective, comprehensive approach that – together – can make a positive difference for people with autism.

- **Presume Competence**
- **Follow the Lead**
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A note about language: In the sections that follow, the pronouns "he" and "she" are often used interchangeably, despite the fact that autism is more prevalent in males than females. Also, while we believe that considerations presented here are helpful in supporting both children and adults with autism, the word "child" and examples of early intervention are frequently presented below, as existing research studies and evidence-based practices have focused more on children than adults.

1: Presume Competence

Without using speech or accurately moving your body, answer the following question: What's your favorite color? What should someone conclude from your awkward response, assuming you did anything at all? Should they conclude that you don't understand the concept of color, and spend the next few months teaching you colors? Of course not. A test that requires you to speak or initiate accurate movement in order to answer isn't necessarily a test of your knowledge. Unfortunately, that can be a problem for people with autism.

Researchers define "praxis" as the ability to execute skilled, goal-directed movement plans and sequences; that is, translating the intention to act or speak into actual behavior.[4] [5] [6] Movement difficulties are among the earliest observable signs of autism,[7] [8] [9] [10] and early motor skills are highly related to later outcome measures for these individuals.[11] Importantly, praxis in children with autism is strongly correlated with the extent of their social, communicative and behavioral challenges, and this relationship is significant even after controlling for differences in basic motor skills.[12] [13]

Science has not yet found a way to look inside of the brain of a person with autism to determine the quality of his or her thoughts. Instead, we use tests that quietly rely on the ability to speak or move accurately, and believe we've measured intelligence. Yet there is a strong correlation between measures of motor function and measures of intelligence on standard tests,[14] [15] [16] [17] and individuals on the autism spectrum show discrepantly higher performance on tests of fluid intelligence and processing speed (thinking and reasoning) compared with their performance on standard IQ tests.[18] [19] [20]

It is also true, however, that tests of fluid intelligence are not strongly correlated with "crystallized intelligence," which is based on the accumulation of facts and experience.[21] It's quite possible for an individual to have the ability and intelligence to think, reason and learn, but to score poorly on measures of crystallized intelligence because he has not been offered adequate exposure to facts, experience, and learning opportunities.

Somehow we've come to accept that if a person cannot answer a question with his body, he must not know the answer in his mind. This is a dangerous assumption, because it can cut off opportunities and access for people with autism, limiting what they can learn based on what they can *demonstrate* rather than what they may actually be capable of understanding, learning, and enjoying.

Similarly, science has not found a way to look into the heart of people with autism and measure their empathy. So what did researchers actually do to measure "empathy"? They played a game with two dolls and a marble (the "Sally-Anne test"). Because people with autism perform differently on that cognitive task than their typical peers, and that performance is equated with "empathy," people with autism are often assumed to lack central aspects of their humanity.

What we believe about people with autism often has more to do with our measurement tools than with the people themselves.

If we wrongly assume that a competent individual cannot learn and understand, and restrict her opportunities as a result, we've done her a great disservice. If we wrongly assume that a person with autism cannot feel love or enjoy friendship, we've also deprived him the chance to share in the deepest aspects of human experience. In contrast, suppose we assume that a person with autism is competent, and we are incorrect. In that case, we may not have been efficient, but our effort and attention may still provide benefit to that person.



In short, the presumption of competence is what researcher Anne Donnellan has called the "least dangerous assumption": in the absence of absolute evidence, it is essential to choose the assumption that, if proven to be false, would be least dangerous to the individual.[22]

Eight Ways to Presume Competence

1) Recognize that there may be a significant difference between what people understand and what they are able to demonstrate. Don't limit the information you offer to a person with autism based on whether he is able to pass some sort of test.
2) Talk to people with autism in an age-appropriate way. Even if a person seems to benefit from fewer words, softer speech, or clear delivery, avoid speaking to people with autism as if they don't understand spoken language (unless their hearing is actually known to be impaired), or as if they are babies.
3) Find ways to support communication through words, picture symbols, sign language, speech-generating devices, or other methods. Even if a person with autism may only be skilled at requesting, treat her with the presumption that she also has a rich set of thoughts, feelings, opinions, and ideas that she may be unable to express.
4) Acknowledge the person with autism as you would a neurotypical person. Avoid speaking about him in his presence as if he were not there. Instead, speak to him directly or refer to him with the same respect as you would offer anyone else – even if he isn't able to respond.[23]
5) Hold up your side of the conversation even if a person with autism is unable to hold up hers. Talk about the news, sports, family issues, politics, science, celebrities, and all of the other topics that might be of interest to a person of the same age.
6) Expose people with autism to age appropriate content in the same variety of subjects that are of interest to others. Try not to assume that knowledge must be "useful" in order to be interesting or worthwhile. There's nothing wrong with adapting the materials used to teach certain content, the pace of delivery, or even the difficulty (though excessive simplification often quietly signals an assumption of incompetence). People with autism should not be denied the opportunities for learning and education that are available to others.
7) Remember that behavior typically serves a purpose. What may seem like useless behavior such as flapping hands, spinning, or other activities may actually be ways that a person with autism uses to regulate his environment to keep him from being overwhelmed. This means that before we try to extinguish or control a behavior, we need to try to understand the *purpose* that the behavior serves, and find some possibly more effective way for that person to meet the same need.
8) Recognize that "problem" behaviors are often the only means of communication that some individuals with autism may have. Behavior that seems "out of the blue" is often related to some subtle denial or frustration. Be careful to observe whether some routine was inadvertently changed, some desired object or activity was denied, or something in the environment is different. Look for ways to help the person meet the same or similar need in an appropriate way.

Self-Efficacy: Presuming Your Own Competence

Researchers in applied psychology often use the term "child efficacy" to describe the belief that a child is capable of learning and improving. Likewise, the term "self-efficacy" is used to describe our own beliefs that we as parents or teachers are capable of helping a child to improve. It's critical not only to recognize that a child can learn, understand, and improve, but that we have the ability to help.

The beliefs that parents and teachers have about their own abilities have an important effect on later outcomes for children with autism and other challenges. Greater parent efficacy results in more positive interactions with children, decreased coercive discipline, improved classroom behavior, reduced behavior problems, lower family stress, reduced parental vulnerability to stress and depression, and increased satisfaction with family life. These outcomes have been reported even after controlling for a wide variety of other factors.[24]

Our beliefs that we are capable of helping are more than just happy feelings – they affect the amount of time we engage with people with autism, the quality of our teaching efforts, how frequently we offer them learning opportunities, and how patient we are in resolving difficulties.

In a longitudinal study of children with disabilities and behavior problems, parental optimism/pessimism was the single best predictor of which children would have more severe problems years later.



This finding was true even though some of the more optimistic parents had children with more severe challenges at the beginning of the study.[25]

Autism researcher Mark Durand describes several key differences between positive and negative "attributional styles": Pessimists often blame themselves or others for negative outcomes, but find it difficult to view positive outcomes as something they accomplished. They also tend to view negative outcomes as permanent and likely to affect many aspects of their lives, while viewing positive outcomes as temporary and due to special factors or luck.[26]

Here are a few simple "mindfulness-based" and "cognitive-behavioral" strategies that may be helpful in shifting to a more positive attributional style, particularly in stressful or crisis situations.

1) **Mindful breathing.** This can be done anywhere, and can be helpful even in situations that have escalated to near-panic:
    a. Take one in-breath, focusing your attention on that in-breath from start to finish.
    b. Breathe out, focusing your attention on that out-breath from start to finish.
    c. Now breathe in mindfully while intentionally calming your body.
    d. Breathe out, while intentionally smiling, however small that smile may be.
    e. What you have just done is to stop your cycle of thinking, if only for a moment, which takes you off "autopilot" and gives you a chance to examine your thoughts objectively and to become fully aware of what is happening in the present moment.

2) Compassionate role-reversal:
    a. Imagine yourself as a 5-year-old child – vulnerable and able to be easily hurt or affected by things you can't control.
    b. Now imagine yourself as a 5-year-old child with autism, perhaps unable to express needs, or to navigate social situations.
    c. Finally, look at the person with autism you are supporting, and imagine that your 5-year-old self with autism has now become that person. Suspend your judgment of whether a particular situation or behavior is "good" or "bad" and instead simply examine it mindfully, asking what is the best action you would want someone else to take if you were that person with autism.

3) **Become aware of your "self-talk":** this is the collection of thoughts that you quietly say to yourself in various situations throughout the day. Don't judge yourself for those thoughts, but instead, become aware of whether your self-talk enables you or disables you. The most disabling forms of self-talk for a parent or teacher are phrases like "I can't take this," "I never know what to do," "I'm an awful parent," or "This will never stop." These thought patterns can lead to giving up or avoiding engagement, and can contribute to a sense of helplessness.

4) **Replace disabling self-talk**:
    a. **Disputation** – Ask yourself whether what you are thinking is really true, and whether the thought is really useful. Thoughts that include "never" or "always" are usually untrue. Thoughts that center on your weaknesses can prevent you from remembering all of the positive skills and approaches you can bring to bear on a given situation.
    b. **Distraction** – It is sometimes said that "logic will not change an emotion, but action will." If it's possible to take a break from a difficult situation, engaging in some positive activity – a walk, meditation, gardening – can be helpful in restoring perspective. If it is not possible to leave, it may help to focus on conscious breathing, and to simply become mindful of everything going on around you in the present moment without judging any of it as "good" or "bad": sounds in the room, people, the sights around you, sensations in your own body, what is happening outside. Even these short episodes of "mindfulness" can bring you back to your "better self" and enable you to approach the situation in a fresh way.
    c. **Substitution** – Choose a realistic thought that focuses on some positive aspect of your child or your own abilities. Examples might include "I am learning approaches to help my child improve," "My child is making progress," and "I am a good parent even if strangers don't understand what is happening in this moment."

Of course, the best thing you can do to improve your sense of "self-efficacy" is to learn effective, evidence-based approaches that can enable you to support others with autism in a positive way. The remainder of this manual focuses on these skills.

2: Follow the Lead

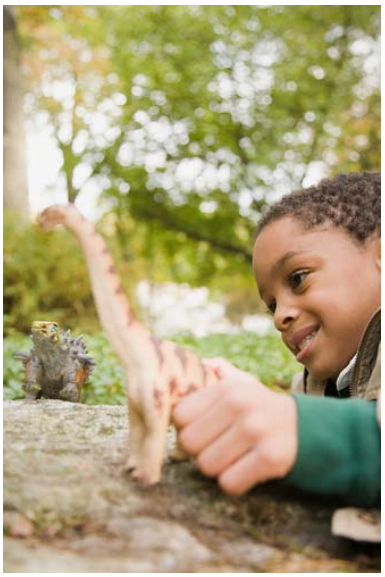
More than a century ago, the American educator John Dewey set out a general principle that a growing body of research has repeatedly found to be particularly important in teaching and supporting individuals with autism: the doorway to learning is to *follow the lead* – by building directly on what is meaningful and desirable to them, and is therefore *automatically* interesting to them:

"Interest is obtained not by thinking about it and consciously aiming at it, *but by considering and aiming at the conditions* that lie back of it, and compel it. If we can discover a child's urgent needs and powers, and if we can supply an environment of materials, appliances, and resources – physical, social and intellectual – to direct their adequate operation, we shall not have to think about interest. It will take care of itself. For mind will have met with what it needs in order to *be* mind.

"I know of no more demoralizing doctrine – when taken literally – than the assertion of some of the opponents of interest that *after* subject-matter has been selected, *then* the teacher should make it interesting. This combines in itself two thorough going errors. On one side, it makes the selection of subject-matter a matter quite independent of the question of interest – that is to say of the child's native urgencies and needs; and, further, it reduces method in instruction to more or less external and artificial devices for dressing up the unrelated materials, so that they will get some hold upon attention.

"In reality, the principle of 'making things interesting' means that subjects be selected in relation to the child's present experience, powers, and needs; and that (in case he does not perceive or appreciate this relevancy) the new material be presented in such a way as to enable the child to appreciate its bearings, its relationships, its value in connection with what already has significance for him."

John Dewey,[27] Interest and Effort in Education, 1913



One of the hallmarks of autism is the tendency to disengage from joint activities, choosing interests that may seem narrow, unusual, or inflexible. To engage a person with autism, start with those activities, topics, and objects that hold great interest for that person.

Even seemingly unusual interests can also offer a "way in" to the world of a person with autism. Following the person's lead and focusing on what is desirable or important to that person is the first step in restoring positive back-and-forth exchanges that are essential to learning, development, and personal relationships. The goal is to create frequent "circles" of interaction throughout the day: in play, in school, and embedded into the activities of daily living – to give the person with autism reinforcing opportunities to learn and engage – starting with whatever is most desirable or important to them. The basic elements of this process are:

1) **Follow the person's lead.** Begin by being attentive to what interests the person with autism and what is *relevant* to her. In some cases, this can be discovered by presenting choices of activities or materials. In other cases, particularly with young children, it may be difficult to obtain any interest at all in a joint activity. In this case, start with *anything at all* that the child finds interesting. A simple way to encourage joint attention is to create a turn-taking activity around whatever that the person with autism shows interest in or seems to enjoy. Keep it fun!

2) **Create "circles" of interaction.** In a child-initiated circle, the child does something she wishes to do, the caregiver offers help in achieving the goal, and the circle is closed when the child responds or gestures to the parent to accept or reject that offer. In a caregiver-initiated circle, the caregiver presents some sort of request or instruction, the child responds in some way, and any legitimate attempt to respond is rewarded by a pleasant, ideally natural consequence.

3) **Use interruption and drama.** Remember that a circle of communication can often be created simply by inserting some small interruption – a request or opportunity – into ordinary activities of daily living. For example, you might hand a child a juice box, but interrupt or "sabotage" the flow by holding the straw to allow the child to request it (possibly prompting the child by asking "straw?"). You might add some drama to a play activity by creating a little "problem" that a toy or doll needs to solve. You might ask "what's next?" in the course of ordinary activities to provide a chance for the child to "re-start" a desirable activity by responding with words or actions. Remember to keep this fun and rewarding, not frustrating or demanding.

4) **Build outward from those interests to a broader range of activities, words, and topics.** As you expand this range, remember that if the activity stops being enjoyable, the person with autism may also stop learning. Go back to the base of more reinforcing activities if you find you've strayed too far. Remember to intersperse new activities with activities that have already been mastered, which improves confidence and keeps motivation high.

A simple way to encourage joint attention is to create a turn-taking activity around anything the person with autism shows interest in or seems to enjoy. Keep it fun!

Many effective naturalistic teaching approaches are based on a combination of these elements. Autism researcher Stanley Greenspan, who originated the DIR Floortime approach[28] observes that following the child's lead can begin with even the most basic interests or activities:

"The children with ASD and other special needs that make the most developmental progress are those who are engaged during most of their waking hours in healthy learning interactions tailored to their unique developmental needs… Many of these activities are what parents do anyway with their children. They are best carried out by building on the child's natural interests and wooing her into the activity. The key is to have fun together; always look for signs of pleasure, such as a big smile, happy sounds, and a gleam in the child's eyes.[29]

"Follow the child's lead, regardless of where his interest lies. But what if a child's interests are unusual or peculiar or are not things we want to encourage? This should not be a concern at this point, because only by joining in the child's interests, by following his lead, do we get a first clue about what he finds important.[30]

"If a caregiver tries to distract the child by offering something the caregiver wants her to be interested in, the child may retreat into her own world, feeling the caregiver isn't interested in what she cares about. . . . If a child is rubbing a piece of cloth over and over, you might slowly move your hand to where she is rubbing, so that now she is rubbing your hand. Thus, you begin to enter her world through her lead and perhaps entice her into an interaction.[31]

"For the child who wanders aimlessly around the room, we have a game we call Moving Fence: I follow the child around and then put my arms around her without actually touching her, so that to get out of the fence and move around the room, she's got to lift my arm, say 'Let go,' or gesture in some way. As

soon as she does, obviously I follow her initiative. The number of different ways to get two-way communication going is inexhaustible – simple peekaboo games, hide-and-seek, rhythmic coordinated activities, and so forth. . . . The key objective is to help the child become keenly motivated. And that requires returning to the basic principle of following the child's natural interest. . . . Getting to a continuous flow of back-and-forth communication is the goal – going from two or three circles, to five, ten, twenty – to the point that circles don't need to be counted anymore because the child can get into a back-and-forth rhythm with you for as long as you're available to help her do it.[32]

"Whenever you feel stuck, take a step back, relax, and observe what the child is doing. The child may not seem to be doing much; she may just be playing with her own fingers. But that is something. A child is always doing something. Ask yourself how you can build on it. Joining one of your fingers with hers, or any other strategy that helps your child relate to you, could work.[33]

"Avoid simply repeating what the child is doing – though you might want to do that for a minute or two just to get your bearings and allow the child to feel that you're in tune with her. Also avoid inventing a challenge of your own that is not related to the child's interests. You can, of course, make available toys or activities that you think might interest the child."[34]

Just give him the whale!

A rich body of research demonstrates that strategies that allow choice and follow the lead of the person with autism are highly effective in producing improvements in communication, reductions in disruptive behavior, and generalization across settings. Very often, individuals with autism experience impoverished conditions and control by others that we ourselves would probably find intolerable. Not surprisingly, problem behaviors decrease as the opportunities to choose preferred activities, recreational activities, and reinforcers are increased.[35] Kluth and Schwarz[36] offer an instructive example:

"Pedro, a little boy with autism, was screaming in his kindergarten classroom on the first day of school. Ms. Gomez, the principal, heard the child's cries and walked into the room. She observed two colleagues discussing the appropriate way to deal with the situation. It appeared that Pedro had started crying because the kindergarten teacher had taken away his favorite whale toy. Believing that her new student would be more successful without the `distraction' of his favorite possession, she had decided to try and hide it from him. The teacher's co–teaching partner, a special education teacher, had a different perspective on the situation. 'What do you want him to do?' she asked her colleague. `I want him to do his work. I want him to participate,' answered the kindergarten teacher. The special education teacher thought for a minute and replied, 'Then just give him the whale.'"

Incorporating the interests of children with autism can also be an important motivational element for improving social interactions. Baker, Koegel and Koegel[37] taught typically developing children to play tag on a large outline of the United States for a child with autism that had a strong interest in maps. Leveraging the child's interests in this way resulted in a dramatic increase in social interactions that generalized to social interactions during other play activities, and were maintained at follow-up. Similarly, in a study of 23 children and youth with autism, Winter-Messiers[38] reported that interactions focused around special interest areas were strongly related to improvements in social, communication, emotional, sensory, and fine-motor skills.

Enhancing motivation

Autism researchers Robert and Lynn Koegel originated an approach known as Pivotal Response Training (PRT), which includes specific procedures to incorporate motivational elements into teaching activities, based on four principles.[39]

1) **Provide child choice:** materials used to teach verbal communication should include toys and activities that are extremely motivating to the child, while providing opportunities to express communication;

2) **Intersperse acquisition and maintenance tasks:** balance opportunities between easier words and tasks that have already been mastered with opportunities to learn objectives that are more difficult for the child. This mixture helps the child to feel successful, and keeps the child motivated to learn;

3) **Reinforce attempts:** In the early stages, it is important to reinforce any functional verbal attempts even if they do not sound like the adult pronunciations. Attempts should be rewarded so that the child learns the connection between verbalizations and the desired outcome of obtaining the requested item. Remember to only reinforce verbalizations that are free of inappropriate behaviors, so that these behaviors are not inadvertently reinforced as well;

4) **Provide natural, contingent reinforcement:** this includes providing immediate access to rewards that are directly related to the language opportunity (as opposed, for example, to delivering a piece of candy as a reward for saying the word 'ball'). The goal is to create a clear connection between the vocalization and the desired object, which makes verbal communication meaningful.

Koegel and Koegel[40] identify several important factors to include when teaching skills to children with autism:

- ✓ **Child attending:** You must have the child's attention prior to presenting a learning opportunity;
- ✓ **Clear opportunity:** The question/instruction/opportunity offered must be clear and appropriate to the activity;
- ✓ **Maintenance tasks:** Intersperse tasks the child can already perform with new tasks;
- ✓ **Multiple cues:** If appropriate to the child's developmental level, the question/instruction should involve the use of multiple cues (e.g. asking the child if he or she wants the blue ball or the red ball);
- ✓ **Child choice:** Offer and follow child choice of tasks and activities. However, intervene if the child engages in hazardous or inappropriate activities. If the child does not show interest in the current activity, attempt to change it;
- ✓ **Contingent:** Reinforcement should be contingent on the child's behavior. For example, giving the toy should be dependent on the child saying "toy";
- ✓ **Natural:** Reinforcement should be natural or directly related to the desired behavior;
- ✓ **Contingent on attempts:** Any goal-directed attempt to respond to questions, instructions or opportunities should be reinforced. Although an attempt does not necessarily need to be correct, it has to be reasonable.

While research and evidence-based practices in autism are most well-established with children, similar considerations can be applied to teach and support adults.

3: Make Communication the Centerpiece

"We must first prepare the person who is not speaking through very simple language stimulation methods that *require thought* and structuring simple language utterances during activities of daily living. Speech is stimulated first by asking a question which requires *thought* by the person it is directed toward, prior to their answer. Once the individual is able to *think* and answer the question with simple spoken language, speaking *confidence* improves. The focus of therapy continues to be stimulating *thought* with simple to more advanced questions, which in turn leads to increased expansion and expression of spoken words.

"Remember this: Where there is interest there is mental attention. Mental attention is therefore related to how much interest your [person with communication difficulties] has in the subject at hand. . . . I want to create a speaking situation that is as *natural* as possible. Communication exchanges occur around things the [person] is passionate or knowledgeable about, things he will want to talk about, and topics that he likes, appreciates, or enjoys."

Mark Ittleman, The Teaching of Talking[41]

Imagine if every time you wanted to say something, you had to carve it out of a block of stone.

For people with autism, speech and communication can be enormously difficult. Without a way to express needs, desires, feelings, or opinions, the only way to communicate is often through behavior. These behaviors are often enormously challenging, and vary widely from individual to individual because every non-verbal person with autism must essentially invent his or her own language, using whatever strategy or behavior – including self-injury – proves necessary or efficient in getting his or her needs met.

There are essentially four steps to teaching and expanding communication for both adults and children with autism:

1) **Follow the lead and interests of the person with autism:** The first objective is to find or create opportunities throughout the day where the person with autism will find it *desirable* to express a thought. Keep the activities animated, fun, and focused as much as possible on the person's own interests.

2) **Provoke thought:** Speech and communication are reflections of thought. While it is possible to teach someone to speak a word from a flash card in order to obtain a piece of candy, these efforts typically do not generalize well. We speak to share a *thought* that has some personal importance to us – whether that thought is a request, a feeling, or an observation. Provoke thought using open-ended questions like "What happened?" or "How would you ask for that?", and statements that invite a response such as "You look like you enjoyed that." Thought provocation asks a question or creates a situation that requires thought or engages reasoning, and provokes the *participant's own construction* of the idea to be communicated – but without explicitly providing the words.



3) **Provide a clear model:** If the person needs more support, offer a clear model of what the person should say, or show how to produce a response using pictures, sign language, or assistive technology. A model involves directly providing part or all of the communicative content. Depending on the person's communication skill, the model may be a single clearly-spoken word "Water?", a choice "Water . . . or Juice?", or a phrase "If this is too hard, say: 'I want a break.'"

4) **Reinforce:** In order for speech and communication to occur, there must be a predictable benefit for the effort. Reinforce any reasonable attempt to speak the model word or phrase. Don't hold out for perfection, especially at first. After you reinforce, you can offer the model again for clarity "Yes! Water," but the objective is to make speech and communication as rewarding and enjoyable as possible.

Where to Begin?

In choosing what to teach, it's important to select vocabulary, phrases and topics based on their *relevance* to the individual with autism. It's tempting to select words from some list of frequent or "functional" words. Again, however, the purpose of communication is to express individual thoughts and desires.

The most motivating way to teach communication is to tap into whatever is most interesting or urgent to that person.

"First words must mean something to a child. First words must have intense meaning for a child. They must be part of his being. . . .Pleasant words won't do. Respectable words won't do. They must be words organically tied up, organically born from the dynamic life itself. They must be words that are already part of the child's being.

"By *organic* I mean that way of growth where the strongest thing pushes up ahead of the less strong. I think of trees growing in a clump. The strongest get to the light. In speaking of a child's mind I mean the strongest impulses push up, irrespective of whether or not they should, at a given time."

- *Sylvia Ashton-Warner*[42]

The most natural way to engage someone's interest in learning language is to observe the person and ask "What is she thinking about?" If a child finds it intensely engaging to dangle a piece of string in front of her eyes, the best first word may be "string." If a child finds it incredibly rewarding to be tickled, the best first word may be "tickle." Begin with labels of objects and activities that are rewarding to that person, and where those actual objects and activities can be immediately delivered on every legitimate attempt, without requiring clarity or perfection at first. You can work on articulation, volume, and sentence length later. First show that language is effective in expressing thought, and *immediately* results in desired outcomes.

Gradually embed the use of words and sentences into every activity of daily living. Initially, you can prompt for various phrases: "Say: ___." As the person becomes more skilled, fade the verbal prompt, and simply point, and then fade the point to an expectant look. If the person doesn't respond, shift back to a greater level of prompting. Encourage frequent use of speech, not only to request, but to comment. It may help to model sentences that give a voice to what the person may be thinking ("It's loud in here." "This is fun!").



First Words

Lynn Koegel describes how a strategy focused on following the child's lead can be used to teach first words.[43] To provide the most useful guidance, Koegel's specific advice is presented below in quotations without adaptation.

1) **First find something that is so important to the child that it is *worth* the effort of speaking:** "Reinforce, reinforce, reinforce. By using an item that your child already likes and wants, you're providing a 'natural reinforcer' for his attempts at language, putting it all in a meaningful context. . . . Because the right reward is so crucial, our clinic playrooms look like toy stores. We want every kid to be able to find something in there that he really wants, and we know that different kids will be captivated by different things."[44] Activities can also be used as rewards. For example, if a child enjoys being tickled, holding your hands expectantly over the child, ready to tickle on request, can offer a desirable reward.

2) **Model the words:** "Hold that favorite object up. Now 'model' the word for the child – that's a fancy way of telling you to say its name. Clearly and distinctly. Try not to say anything more than the object's label during this initial step, or you may confuse your child."[45] Wait for any verbal response at all. If it sounds anything like the word, give the object to the child immediately. If the child has trouble saying a whole word, prompt for a sound (for example, "Shhh" can be a word for water). Model the word clearly, but don't force the child's lips, and don't force eye contact.

3) **Encourage spontaneous language:** Once the child can identify several desired words and activities, "fade" the model by showing the child the desired item without offering him the word. Give the child the opportunity to say the word on his own. If the child doesn't do so, then go ahead and model it, but continue to offer opportunities for more independent speech.

4) **Keep things social and interactive:** "Words need to be developed in the context of meaningful and functional interactions. Using real toys, taking turns, and using those toys functionally help the child begin to develop a sense of sharing and what it takes to be a good playmate . . . a lot more opportunities for language gain will arise while you're playing."[46]

5) **Gradually broaden from requesting to conversation:** Once a child can say many words independently, begin to string two or three words together. For example, adding "no" to a word, or "more," "open," "close," as well as colors, shapes, numbers, and so on. Koegel observes "we want the child to use all kinds of new and novel two-word combinations. That is the start of true sentence use."[47] Children can also be taught verbs using materials that move, such as pop-up books, and asking "what's happening?" or "what happened?"

6) **Encourage initiations:** Once a child can request spontaneously, children can be taught to initiate questions on their own. "Once again, we want you to motivate your child by collecting a bunch of favorite items, only this time put them inside an opaque bag and let him know they're in there. Once you have his attention, you're going to model the question you want. Say 'What's that?' then pull out one off the desired items. Put the item back in the bag and let your child know it's his turn to try. If necessary, prompt him by repeating the question – but you may not need to. Once your child says or repeats, 'What's that?' take out one of those desirable items, label it, and hand it to him. We've found that it doesn't take more than a few sessions of practice before your child will happily keep asking 'What's that?' to get more and more of the

unknown, but desired, items out of the bag. . . . To teach your child to ask, 'Where is it' hide one of his favorite toys and play a game of finding it. Model saying, 'Where is it?' then answer your own question with 'Under the sofa,' or wherever you've put it, and then uncover the toy."[48] Similarly, children can be taught to initiate 'What happened?" and other phrases. The ability to initiate questions like this is viewed as a "pivotal" skill because it opens up the opportunity for the child to ask and learn about an endless range of subjects that are of interest to him or her.

Scaffolding

Jerome Bruner, one of the leading theorists in language acquisition, emphasized the importance of social interaction between the child and a linguistically competent adult in the development of language. The interaction and collaboration provided by the adult, typically during predictable routines and ordinary activities of daily living, bridges the gap between the child's existing abilities and those that the child is capable of achieving. Brunner used the term "scaffolding" to describe the support provided by an adult to help the child move from what is already familiar to what is not: "it refers to the steps taken to reduce the degrees of freedom in carrying out some task so that the child can concentrate on the difficult skill she is in the process of acquiring."[49]

It is difficult to overstate the importance of social interactions that expand and scaffold around the existing interests and abilities of the child. In a study of early language acquisition among 24 children, activities involving joint attention between parent and child, such as playing together with a toy, produced more comments, conversations, and utterances from the children than were observed outside of those activities.

The more often parents made references (such as comments and new words) that related to objects already in the focus of the child's attention, the larger the child's vocabulary tended to be 6 months later.

In contrast, references that attempted to redirect the child's attention were negatively correlated with the child's vocabulary. None of the activities from outside of the joint attentional interaction were related to the child's later language. In short, words that are taught in relationship to objects that *already* hold the child's attention are typically learned better than words that attempt to redirect the child's attention.[50] Changes in spoken language among children with autism are primarily determined by a) how often parent utterances follow the child's focus of attention, and b) how often parent utterances respond to the child's verbal attempts.[51] More than any other adult utterance, prompts that continue a child-initiated topic are most likely to elicit multi-word child replies.[52]

Parents and teachers provide a scaffold each time they expand an already familiar concept by asking leading questions ("What else do you see?") or elaborating new details. As the child becomes more independent at one skill, the support is gradually reduced (called "fading") and skills are broadened.

Scaffolds such as alternative and assistive communication (AAC) devices, picture communication systems, and initial typing support can also help bridge the gap between the child's existing skills and their full capabilities. Verbal language requires the motor system to be recruited, with a particular link between speech and manual gestures.[53] The emergence of speech has in some cases been reported to follow the ability to communicate in ways that engage movement, such as typing or signing.[54] Children who have a low tendency to imitate verbal modeling appear to learn more when verbal language is taught alongside sign language.[55] While parents are often concerned that using multiple modes of communication will be confusing, a "total communication" approach also appears to be most successful with children with echolalia.[56]

Engage reasoning, provoke thought

When teaching new words or information, remember not only to give instructions but also to ask questions, engage reasoning, and provoke *thought*. This can be done even with minimally-verbal individuals, by first asking a question before providing the word or the model (e.g. "What is this? [*pause*] It's juice. Say: JUICE.").



Once you have the person's engaged interest, new vocabulary and even more advanced content such as math, science, and other information can also be taught by "branching" from idea to idea in a way that provides a constant flow of new information. Here is a simple example of how branching might be used during play time.

1) **Provide new information.** For example, if a child is playing with the wheel of a toy car, point to the wheel and ask "Do you know what this is? [*pause*] It's a wheel. Say: WHEEL."
2) **Consolidate the new word or concept.** In addition to teaching the word verbally, you can also write the word on a small piece of paper, support the child in typing the new word, teach the sign language equivalent, or use a combination of modalities that simultaneously combine language and movement or gesture.
3) **Engage reasoning.** Ask a question to provoke thought about the new information. Large differences are easiest to discriminate. For example, point to the wheel and ask "Where does a WHEEL go?... On a CAR or on a BIRD?" then pause, and depending on whether a correct response was offered say, "Yes! The WHEEL is on the CAR. Say: WHEEL," or just "The WHEEL is on the CAR. Say: WHEEL." Reinforce every legitimate attempt. Keep it fun!
4) **Watch the child and look for cues to introduce new information.** Expand on the existing topic with new and related details: For example, spin the wheel and say "Look! What does a WHEEL do? It SPINS! Say: SPIN."
5) **Repeat with additional circles of interaction and reinforcement.**

When teaching adults, the use of toys may be less appropriate, but the use of pictures or manipulatives may be helpful, and the same branching approach can be used to teach content that is of interest to the person with autism.

The central technique is the same: provide new information; reinforce the new word or concept through writing, typing, sign-language or other modalities that ideally combine language and movement or gesture simultaneously; engage reasoning by asking a question to provoke thought and discriminate the new information; and then branch (scaffold) from each successive point to introduce a chain of additional concepts.

In general, the teaching situation should be structured to avoid highly repetitive and narrow prompting, in preference for more general questions that allow multiple ways of responding. Begin by asking open-ended questions that provoke thought. Language-impaired children whose parents used proportionally more information-seeking questions showed greater mastery and variation of language use 12 months later.[57] If you think the person knows what he or she wants to say but may need extra support, you can offer a sentence-starter or prompt the first sound of the word, and allow the person to fill-in the rest of the response. If the person with autism needs more support (or if he or she is only starting to learn how sentences are formed), move to offering a full model.

Thought provocation involves asking a question or creating a situation that engages thought or reasoning. The goal is to provoke a thought to be communicated – but without explicitly providing the words. A *model* involves directly providing part or all of the communicative content. The following table illustrates thought-provoking questions and partial models that might precede offering a full model:

Thought provocation / open-ended question	**Partial model**	**Full model**
Can you tell me what you want?	I want …	Say: I want a cookie
What happened?	It …	Say: It fell down
How would you ask for that?	Open …	Say: Open the box
You look like you enjoyed that!	I had …	Say: I had fun
What should we do with the water?	P …	Say: Pour it in the bowl
Where did it go?	It went …	Say: Under the bridge
What is she doing?	She is …	Say: She is running away
Who is chasing her?	The three …	Say: The three bears
What is it made of? [*pause*] Wood or stone?	It is made of …	Say: It is made of wood

4: Offer Positive Behavior Support

Behavior is not random, but is instead motivated by necessity, desire, or the need to communicate. This is not the same as saying that all behavior is *intentional*, as many behaviors in autism may be driven by compulsive impulses that are difficult to control. Still, behaviors that seem "out of the blue" can often be traced to some event that preceded it: a subtle denial of a request, an unexpected change in routine, a disappointment, an overwhelming sensory experience, or a frustrating demand.

The central point is that behavior has a purposeful function. Because some behaviors in autism can be extremely challenging and even self-injurious, the goal of controlling or changing the behavior of people with autism is often high on the priorities of others. The problem with this objective is that it often ignores the *function* that the behavior serves, or worse, exposes people with autism to coercion, punishment, seclusion, and other treatment that neurotypical individuals would never find acceptable.

Think of behavior in autism like a long balloon. If you try to squeeze the air on one side of the balloon, it simply pops out somewhere else. Unless the underlying need is addressed, attempts to suppress inappropriate or undesirable behaviors in autism often result in the emergence of some replacement behavior that may be even less desirable.

Whose problem is it?

Keep in mind also that many behaviors in autism that seem unusual or inappropriate are actually adaptive solutions that a person has discovered to compensate and negotiate within his environment. A child may go through the day with her hands over her ears because she is unusually sensitive to noise or other forms of sensory overload. A person with autism may be inclined to spin, twirl, or rock from side to side in order to get enjoyable or compensating input to his vestibular system (the system that helps us feel the position and movement of our body in space). A person with autism may flap his hands, verbalize phrases or noises, bite his wrist, and so forth – not out of willful disobedience or a desire to look different, but because these behaviors help him deal with anxiety, excitement, or a sensory system that is excessively or insufficiently activated.

Before attempting to "manage" a behavior, think carefully about how that behavior may be helpful, useful, or even needed by the person with autism.

Behaviors can often be addressed by finding an accommodation (headphones, sensory toys, periodic breaks, access to swings), encouraging a replacement behavior that addresses the same need, or teaching a communicative alternative (phrases like "I don't understand" or "I need a break," or picture cards, signs, or gestures). *Our goal is give the people with autism a way to achieve their needs more effectively than with the existing behavior.*



In contrast, efforts focused primarily on making those with autism "look indistinguishable from their peers" often reflect an unwillingness to accept differences in others or to make accommodations for them. We should be hesitant to "manage" behaviors that are useful and adaptive to a person with autism simply because they seem unusual or peculiar.

Key ideas

The objective of positive behavior support is to first identify the *function* that a given behavior serves, and then to teach a replacement behavior that serves the same function, or a communicative

alternative that is *more efficient and reliable than the behavior* in ensuring that the underlying need is met.

Behavioral researcher Edward Carr[58] proposed the following six considerations in regard to communication-based intervention for behavior problems:

1) **Problem behavior usually serves a purpose:** Rather than being random or aberrant, problem behavior can be adaptive, and that is why it is displayed so often. If a young girl learns that the only way to get her father's undivided attention is by banging her head against the table, then head-banging becomes a useful and adaptive response because it guarantees that the girl will receive continued contact and interaction with a very important person in her life.
2) ***Functional Assessment* can be used to discover the purpose of the problem behavior:** Because problem behavior is typically purposeful, you cannot change it successfully in the long run without trying to discover the purpose of the behavior, its triggers, and its consequences.
3) **The goal of intervention is education, not simply behavior reduction:** The main goal of intervention is to teach the individual new ways of influencing other people so that the problem behaviors are no longer necessary.
4) **Problem behavior can serve many different purposes that require different interventions:** It is usually wrong to think that you can affect all of an individual's severe problem behavior in the community by using a single intervention procedure.
5) **Intervention involves changing social systems, not individuals:** Intervention is not something you do *to* a person who has disabilities; rather, it is something that you do *with* a person who has disabilities. . . . It implies the process of mutual give and take and of reciprocal influence, which leads to desirable behavior change on the part of everyone involved.
6) **Lifestyle change is the ultimate goal of intervention:** The broader goal of intervention is to produce change that positively affects how people live their lives. . . . Problem behavior, more often than not, emerges from a background of exclusion, segregation, lack of personal control, and impoverished lifestyles. . . . Successful interventions permit an individual to participate directly in the community, and have more social, vocational, and leisure opportunities than ever before.

When faced with a challenging behavior, the immediate question is not "How can this behavior be controlled?" but instead "What *need* does this behavior serve, and how can I help this person meet that need in an appropriate way?"

These are the basic steps of positive behavior support:

1) **Describe the behavior** in a specific, observable, measurable way.
2) **Identify the function** of the behavior. Why is it rewarding? What need does it help to meet?
3) **Identify the triggers** ("antecedents") of the behavior.
4) **Teach a "functionally equivalent" substitute behavior or a communicative alternative**: A person who engages in inappropriate behavior for attention can be taught to ask for attention in more acceptable ways (e.g. asking "Can I join?" to join in an activity or "Can I help you?" to obtain attention without requiring others to discontinue their own activities). A person who engages in inappropriate sensory activities can be taught how to ask for a sensory break.
5) **Ensure that the alternative consistently results in reinforcement** that meets the underlying need as *efficiently and immediately* as possible.
6) **Remove the reward for inappropriate behavior** ("extinction") to the greatest extent possible.

7) **Avoid punishing the problem behavior**, aside from possibly interrupting it in a neutral way (e.g. gently holding hands down for a few seconds, 30-second time-outs).
8) **Reduce the immediacy of reinforcing the alternative behavior only after sustained success.** Once the frequency of the problem behavior is reliably reduced (but not until then), gradually increase the time delay and reduce the frequency of reinforcement to an appropriate and sustainable level.

Edward Carr and Mark Durand[59] pioneered the approach known as functional communication training or FCT, which addresses severe behaviors by teaching replacement behaviors and communicative alternatives that address the same functional purpose. Later research has demonstrated that combining FCT with "extinction" (removing the reward for inappropriate behavior, typically by ignoring it) can be helpful in further reducing severe and self-injurious behavior.

Importantly, one early study[60] reported gains by combining FCT with "punishment." It is essential to recognize that "punishment" in that study referred to a 30-second period involving time-out, brief restraint such as holding down hands, or in some cases, briefly blocking visual input. These results *do not* support the use of inhumane practices that involve painful stimulus or extended restraint. Rather, it appears reasonable to conclude that there may be a benefit in some cases to *combining* FCT with either extinction or a *brief, non-reinforcing interruption* of the severe behavior, such as a 30-second time-out or holding hands down for a few seconds. This practice should not be used for attention-seeking behaviors, which – beyond protecting the individual and others – should be ignored in the most neutral way possible.

The point is teach a more efficient way for the person to meet her needs, to *withdraw the opportunity to obtain reinforcement* from the inappropriate behavior, and in the case of time-outs, to *create a discrepancy* between the neutral time-out environment and the ideally much more desirable "time-in" environment.[61] After the time-out period is over, look for an opportunity to immediately reinforce the first appropriate behavior that is observed.[62]

Given the demonstrated effectiveness of functional communication training coupled with extinction and brief, non-reinforcing interruption, there is no reasonable defense for the use of punishment techniques involving pain, seclusion, coercive restraint or similar practices. These practices are also generally recognized as violations of the rights and dignity of individuals with autism (despite the somewhat Orwellian view by some practitioners that individuals have a "right" to punishment as a "treatment"). Our view is that these forms of punishment should be excluded from consideration in the treatment of even the most severe behaviors.

Positive behavior support in day-to-day activities: ABC Analysis

A useful way to think about challenging behavior in day-to-day settings is to examine the chain of events immediately surrounding the behavior. There are three questions to ask:

1) Identify the events or conditions – the **Antecedents** – that occurred just before the behavior. Try to identify specific, observable factors such as "working on new math skill," or "turned off music," rather than general emotional states like "became frustrated";
2) Describe the **Behavior** itself in a specific, observable, and measurable way. One can count the number of times "hit head with palm" occurs, but it is more difficult to count "upset";
3) Describe the **Consequences** – what happened immediately after the behavior? Was it rewarded by receiving a desired object or activity? Was the person with autism removed from the room? Who responded and what did they do?

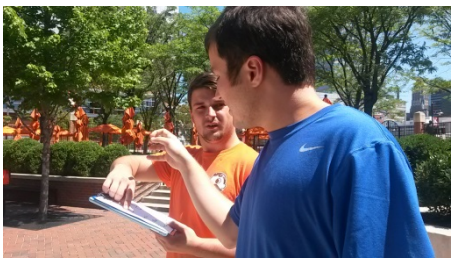
This sort of examination of the Antecedent-Behavior-Consequence sequence is known as ABC analysis.

ABC analysis can be very helpful in day-to-day settings because it immediately focuses your attention beyond the behavior itself, to the factors that may be *causing* it, and the various reinforcements that may be *maintaining* it.

While more detailed analysis and data-gathering may sometimes be needed, ABC analysis often identifies straightforward antecedents (work demands, transitions) that tend to provoke difficult behaviors, as well as items and activities (breaks, music, toys, food, attention) that are the desirable and rewarding objectives of that behavior.

When you identify an antecedent that is undesirable to the person with autism (e.g. work demands in school), try to increase motivation whenever possible by "following the lead" and using materials that are relevant to the child's own interests. It can also be helpful to offer choices even for simple aspects like the order of problems to solve, or the color of the pen being used.

Predictability



Predictability can be extremely important to individuals with autism. It can be a great relief simply to know when a desired activity will happen, or when an undesirable activity will end. Several strategies can be used to increase predictability and extend patience:

1) **Teach "I want a break," "help me," and "I don't understand":** Depending on communication skill, this can be taught using a verbal phrase, picture, or a sign language gesture. Initially, deliver the break or provide help *immediately every time* it is requested. Once the request is well-learned and is only rarely accompanied by undesirable behavior, you can work on extending the time ("latency") before a break or help is given. For non-verbal individuals with autism, easy access to alternative communication or picture systems is critically important.
2) **Use visual schedules:** Use a visual timer, token card (small pictures with Velcro on the back that are used to gradually fill spaces on card to show completion), a checklist that allows the person to mark each item as it is completed, or a picture schedule so the person with autism knows how long the activity is required and what will come next. Visuals should be used as supports, but not so extensively that every day-to-day activity seems restrictive and pre-programmed. As Naoki Higashida, a young man with autism, observes: "when it comes to explaining the order that you do certain actions in, or instructions about how to make such-and-such an object, visual aids, like pictures, can help a lot. But being shown photos of places we're going to visit on an upcoming school trip, for example, can spoil our fun."[63]
3) **First/Then, When/Where:** If a child desires something that is usually available at some point in his day, but he must first do some other activity, respond "YES, FIRST" [and describe the *current* activity], followed by "THEN" [and describe the *desired* activity]. If necessary, you might also say when and where the activity will be available. For example, "YES, we can get lunch. First math, then lunch in the cafeteria." If possible, including visual reminders can be helpful.
4) **More later:** Transitions from a preferred activity to another can be particularly difficult for children with autism. Providing them with advance notice before transitions ("2 more minutes, then more later") and reminding them of future opportunities ("More tomorrow") at the end of the activity can be helpful.
5) **Red light / Green light:** Create a visual cue to indicate whether a desired object, activity, or break will be available if it is requested. When the green light or similar visual is on the table, it

indicates that requests will be honored immediately. When the red light is on the table, it indicates that the person will have to wait.

6) **Build trust:** Follow through on what you promise, and avoid promises that cannot be delivered.
7) **Avoid bribes:** It is not a bribe to offer *predictability* about ordinary privileges, planned rewards, and special events, or to offer a reinforcer that normally follows a desired behavior or skill that is successfully completed. In contrast, bribes are *undeserved, unplanned, and out-of-the-ordinary payoffs* that are offered for stopping an undesirable behavior or producing a desirable one. "Finish work first, then cookie" is a reinforcer if access to a cookie *normally* follows the work, or if cookies are *part of the plan*. "Cookie if you stop crying" is a bribe unless cookies are part of the plan (for example, at lunch or in a bakery). If cookies are part of the plan, a better prompt would be "Sit quietly first, then cookie" to reinforce the positive behavior.

Instead of focusing on managing behavior, focus on helping to *meet the needs* of the person in positive ways and at reasonable times.

It is well-established that low levels of attention from others are typical antecedents for attention-seeking behavior, low levels of external stimulation are typical antecedents for sensory-seeking or automatically reinforced behavior, and the presentation of instructions is a typical antecedent for escape-motivated behavior.[64]



For desirable objects or activities, look for ways to enable the person with autism to have easier access to those rewards (or appropriate ones with similar function) without needing to engage in a negative behavior first. This strategy is variously known as "noncontingent reinforcement" and "environmental enrichment." Building desirable objects or activities – social attention, breaks, snacks, music, sensory activities – into the environment and the daily schedule can reduce the frequency of inappropriate behaviors that might otherwise be used to obtain them.

Alternatively, the desired reinforcer can be provided in response to some positive or appropriate behavior (known as "contingent reinforcement"). In either case, the central idea is to disrupt the relationship between undesirable behavior and the reinforcer, while giving the person with autism greater control over his or her own environment by creating more efficient ways for him or her to obtain desired reinforcers or activities.

Moments of Crisis

What happens if you're in the middle of a behavioral "meltdown" that seems uncontrollable?

1) **Look for the cause.** If you don't know what's bothering the person, you can certainly ask "show me" or "tell me." Mentally run through a quick A-B-C analysis and try to identify the antecedent for the meltdown and the need that has not been addressed. Though many behaviors in autism may appear to come "out of the blue," the source of a meltdown can often be traced to the overt or subtle denial of a desired object or expected activity or routine. Sensory overload in loud or crowded situations can also be a contributor. For many children with autism, once an expectation is firmly planted, it can be very difficult to change course in the moment.
2) **Provide an appropriate reinforcement for an appropriate behavior.** If at all possible, avoid providing a reinforcer as the immediate consequence for the negative behavior. Doing so will tend to increase the frequency of that behavior. Instead, even in difficult situations, limit the

attention you give to the undesirable behavior. Try to encourage the person with autism to engage in some small *appropriate behavior* such as completing a simple task or being quiet for even a few seconds before delivering a desired object, taking a break, or shifting to a requested activity. You want to link the reinforcement with some *positive and appropriate* behavior. In a pinch, you can ask for any neutral, arbitrary behavior at all. Even reinforcing "touch your nose" is better than reinforcing inappropriate behavior. "Catch" the child behaving appropriately, even briefly, and reinforce that. Try to avoid offering out-of-the-ordinary reinforcers, or meltdowns may become a preferred strategy to get them.

3) **Stay calm, pleasant, and matter-of-fact.** Pay attention to your own breathing, which will help you to restore a calm and objective approach. Minimize attention and comments toward the negative behavior.
4) **Redirect.** If the desired object or activity is inappropriate or unavailable, try to redirect the person to the closest appropriate substitute.
5) **Use the word YES.** All of us, including individuals with autism, want to hear the word "yes" as much as possible. Using the word "no" will often escalate the crisis further. Ask for appropriate behavior with "Yes. First ___, then ___." Tell the person what you *want* him to do, not what you *don't want* him to do. Negative instructions in response to problem behavior like "Don't lie on the floor" versus positive or neutral ones like "Sit in the chair" can contribute to problem behaviors.[65]
6) **If you need to give in, give in quickly.** Ideally, reinforcement should be provided only as the consequence of *appropriate* behavior. However, if a crisis is escalating in a public place, and the desired object or activity is not dangerous in and of itself, and you don't think you'll be able to maintain your resolve, *give in immediately*. As Durand observes, "The reason is straightforward: if you think you will eventually give in, give in early, before the behavior problem has escalated. . . . Although this is not a long-term fix for the child's problem, at least he is not learning to increase the severity of his behavior and become more and more disruptive. Let me repeat this: You want to avoid having your child learn to escalate his or her behavior to get what he or she wants."[66]
7) **Protect, but do not restrain or coerce.** In situations that escalate to violence, protect the person, protect others, but try to avoid battles for control. Unless the situation is extremely threatening to the person or others, avoid attempts at coercion and physical restraint. NEVER restrain around the chest or torso, or move the person in a way that prevents him or her from communicating distress. Accidental suffocation is an elevated risk in autism.[67]
8) **De-escalate the crisis.** Your only goal in a crisis situation should be to de-escalate the crisis. Maintain a neutral voice and manner, and try to redirect the person matter-of-factly to a safe location and activity. A meltdown is a signal that something needs to be taught or planned more carefully. While it is best to reward appropriate behavior if possible, a crisis is the wrong time to teach lessons or wage battles.
9) **Reduce the risk of future meltdowns.** After the crisis, focus on making changes that will reduce the risk of similar episodes. Put simply, the best time to handle a meltdown is *before* it occurs. Describe any changes in routine in advance. Visual schedules (picture cards describing the order of activities) can be helpful, as well as "first/then," "when/where," and "more later" reminders. Before going to public settings where food or desirable activities will be restricted, try to offer a snack or brief activity beforehand. Bring headphones (ideally not so large as to be stigmatizing), sunglasses, snacks, drawing items, small toys, or other age-appropriate items when going to places that are noisy or involve a great deal of waiting.

If you find behavior escalating quite often, focus on creating greater predictability, and more frequent opportunities for the person to obtain desired reinforcement on a contingent basis (as a reward for appropriate behavior) or a non-contingent basis (provided automatically as a regular part of the environment or daily schedule). If the desired reinforcement is inappropriate, unavailable, or you don't know the purpose of a given behavior, move on to functional analysis. This will help to identify a replacement behavior that allows the same need to be met.

Finding the function

Generally speaking, behaviors in autism are directed toward one or more of the following functions:

- Escape from an undesirable activity or environment
- Tangible items such as food, toys or other objects
- Social attention, even if that attention is in the form of reprimands
- Sensory or "automatic" reinforcement
- Communicating physical discomfort or illness

Behavioral questionnaires can assist in identifying the function of challenging behaviors. They are generally easily scored, and may provide additional insight beyond what an informal ABC analysis may provide.

Matson and Vollmer developed a short questionnaire, Questions About Behavioral Function (QABF)[68] to assist in understanding the function of challenging behaviors and to increase adaptive behaviors to replace them. The QABF is designed to identify the function of behaviors across five areas: social attention, escape, non-social reinforcement, physical discomfort, and tangible reinforcement. Each item is rated on a scale of 0 (never) to 3 (often). Examples include:

- ✓ Does he/she seem to be saying "come see me" or "look at me" when engaging in the behavior? (Social Attention)
- ✓ Engages in the behavior when you have something he/she wants (Tangible Reinforcement)
- ✓ Engages in the behavior to try to get people to leave him/her alone (Escape)
- ✓ Engages in the behavior even if he/she thinks no one is in the room (Non-Social/Sensory)
- ✓ Engages in the behavior because he/she is in pain (Physical Discomfort)

In clinical settings, the QABF was reported to define a clear behavioral function (a subscale with a minimum of 4 responses and no other subscales containing significant scores) in 84% of individuals. For self-injurious behaviors, the two most prominent antecedents were reported to be non-social reinforcement ("self-stimulation") and escape. Among aggressive behaviors, the two most frequent antecedents were attention and escape. For stereotypical behaviors, non-social reinforcement was the most significant antecedent.[69] Remember however that every person with autism is different, so it is important to look for their own motivations, not just typical ones.

Durand[70] developed a similar instrument called the Motivational Assessment Scale (MAS) to help in making informed decisions about appropriate reinforcers and treatments. Durand emphasizes the importance of identifying behavior very specifically ("aggressive" is not as useful as "hits his sister"). Each item is rated on the following scale: 0 (never), 1 (almost never), 2 (seldom), 3 (half the time), 4 (usually), 5 (almost always), 6 (always). Examples include:

- ✓ Does this person seem to do the behavior to get you to spend some time with him or her? (Attention)
- ✓ Does the behavior occur when you take away a favorite toy, food, or activity? (Tangible)

- ✓ Does the behavior occur following a request to perform a difficult task? (Escape)
- ✓ Would the behavior occur repeatedly, in the same way, for very long periods of time, if no one was around? (Sensory)

Teaching replacement behaviors and communicative alternatives

As Edward Carr observes, the goal of intervention is education, not simply behavior reduction: "The main goal of intervention is to teach the individual new ways of influencing other people so that the problem behaviors are no longer necessary."[71]

We want to find a "functionally equivalent" behavior or communicative alternative that allows the same basic need to be met, but without the undesirable behavior. In order for this to be effective, the replacement behavior must be *more efficient* than the undesirable behavior in achieving the desired goal.

Several considerations are important when teaching replacement behaviors:

- **Initially, every request for the replacement object or activity should be honored.** Again, the replacement behavior must be more efficient than the undesirable behavior in achieving the goal. While this may initially result in a very high frequency of requests, research indicates that as the availability of reinforcement becomes reliable and predictable, the ability to make these requests is not abused.[72] After the frequency of the problem behavior is reliably reduced (ideally by at least 90%), you can gradually increase the time delay and reduce the frequency of reinforcement for the alternative behavior to an appropriate and sustainable level.

- **Research suggests that the alternative behavior is unlikely to be learned if the undesirable behavior continues to be reinforced.**[73] So the teaching of alternative behaviors should be coupled with "extinction" of the reward for the inappropriate behaviors. Aside from protecting the person from harm, the undesirable behavior itself should be ignored in the most neutral and unemotional way possible, so that it no longer results in the desired reinforcement. This is particularly true for attention-seeking behaviors. For severe behaviors that are not attention-seeking, a *brief non-reinforcing interruption* of the severe behavior may be helpful, such as a 30-second time-out or holding hands down for a few seconds. There is no evidence that more aversive restraint or punishment is required, and we view these practices as unethical.

Remember that a great deal can be achieved simply by increasing the ways in which the person with autism can obtain desired objects and activities in an appropriate way.

Behaviors seeking social attention occur most often in environments where individuals are provided little attention in the absence of negative behaviors. Similarly, behaviors seeking tangible objects tend to occur in environments where the availability of desirable objects is highly controlled or unpredictable.

The communicative response chosen should be easy to learn, and easily understood by others. The following are typical replacement behaviors and communicative alternatives to address differing behavioral functions. This list is only suggestive – the specific details and needs of the individual should always drive the alternative that is chosen. Communicative responses can be taught either verbally, or by teaching the person to show a picture card, sign, gesture, or token (small object) representing the desired object or activity.

1) **Escape behaviors:** Teach "break" or "I want a break" for general escape behaviors. Teach "help me" or "I don't understand" where undesirable behaviors are provoked by the difficulty of demands. For example, if the person with autism hits herself or others when asked to participate in a learning activity, estimate the shortest amount of time she is likely to engage in the activity *without* the undesirable behavior, then quickly prompt her to say "I want a break" or help her physically hand you a card showing the word "break." If the undesirable behavior occurs first, respond in a neutral way, remove the teaching materials, or interrupt the behavior with a brief time out. Then return to the activity again and quickly prompt for a break. As soon as she hands you the card or attempts to say the phrase, take a break. As she becomes proficient at handing the card or requesting a break, gradually reduce the level of prompting to simply pointing to the card, or offering an expectant look.

2) Tangible items and activities (non-sensory):

a) For appropriate items or activities, teach "I want ___," "more ___" or teach the request using picture cards or tokens. In general, the request should be granted immediately to the extent possible. If the desired tangible cannot possibly be delivered on request, respond "Yes" but teach the individual to repeat "first ___, then ___" to offer predictability about when the desired item or activity will be available.



b) For inappropriate items or activities, try to find a similar item or activity that could meet at least part of the desired need. Ideally, the person should be offered two or more choices.

3) **Social attention:** Teach "Can I help?" or "Help?" to allow the person to contribute and interact without stopping ongoing activities. "Do something?" can also be taught to provide a way to ask for general interaction, which might be a game, a walk, or another appropriate activity. Try not to think of attention-seeking behaviors as a way to "get your goat" but as a way of feeling noticed and obtaining interaction.

4) Sensory input and reinforcement:

a) For appropriate sensory-seeking, providing regular "non-contingent" sensory opportunities (starting the day with swinging or other movement, providing sensory toys like squish balls, and so forth) can be helpful. Teach requests such as "swing," "tickle," "hug" and other appropriate sensory targets. As with tangible items, if the request cannot possibly be honored on request, respond "Yes" but teach the individual to repeat "first ___, then ___" to increase the predictability of when the desired activity will be available.

b) For inappropriate sensory seeking, the first approach should always be to increase the availability of appropriate sensory input throughout the day. As with tangible items, try to find a similar item or activity that could meet at least part of the desired need. For example, pica (eating non-food objects) can be addressed by offering food items that share similar texture and flavor, such as lettuce or vegetables in place of leaves. Swings, exercise equipment, music players, picture books and videos, sensory brushes, deep pressure to large muscles (never around

the torso or chest), weighted blankets, water, sand, clay or even opportunities to doodle are among the variety of ways to provide physical, vestibular, tactile, auditory, visual, and other forms of sensory input. Ideally, the person should be offered two or more choices.

5) **Physical discomfort:** Teach "hurts," "sick" or the use of the FACES pain-rating picture cards, depicting emotions ranging from "no hurt" to "hurts worst." Physiological research indicates that rather than being insensitive to pain, individuals with autism appear to experience pain to the same or greater degree than others, but express pain differently in their behavior.[74] Even individuals prone to self-injury do not appear to have reduced pain sensitivity,[75] so pain should not be ruled out as a factor in behavior. The Non-Communicating Children's Pain Checklist – Revised (NCCPC-R) is a validated measurement tool[76] that uses 30 items covering vocal and social behavior, activity, body and limbs, physiological symptoms, and eating/sleeping changes to assess pain in individuals with limited ability to communicate.

5: Include and Adapt

"The idea of school inclusion can be a lousy or a lovely happening. It's really all in the hands of the teachers along with the permission from the big boss, the superintendent. Teachers must be willing to not just give me a desk and then leave me to fill the chair. I need to be asked questions, and given time for my thoughtful answers. Teachers need to become as a conductor, and then guide me through the many places I may get lost." – Jamie Burke[77]

Inclusion is not something that a school *has*, but is instead something that a school *does*.

Too often, even when children are placed in inclusive settings, they may be "included in the corner," spending most of their time in activities that are unrelated to those of their typically developing peers, or situated in a different part of the classroom.[78]

The Individuals with Disabilities Education Act (IDEA) guarantees a free and appropriate public education for children with special needs, and provides for an individualized education program (IEP) specifying individual goals, along with special services that will be offered. Importantly, the law indicates that a child should be placed in the "least restrictive environment" (LRE), and may be removed from general education setting only "when the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily." These "supplementary aids and services" include those supports that are needed by the student to meet his or her IEP goals, and may include adapted curriculum, visual schedules, alternative and assistive communication technology, behavior intervention plans (BIPs), paraprofessional support, modified tests, and other provisions.



The educational goals of students with disabilities are specified by their IEP, and it is certainly not true that children with special needs must achieve the same objectives or keep up with their typical peers in order to be educated in inclusive classrooms. Students requiring credit toward a diploma are subject to the academic requirements of their courses, but there is no prerequisite for students with special needs to obtain an inclusive education, as long as their own IEP goals can be pursued satisfactorily in that setting.

Inclusive education means that students with disabilities attend their home school, are educated in regular classes with appropriate supports and services, and participate in the typical routines and traditions of the school (e.g. school assemblies, extra-curricular activities). To the greatest extent possible, related services such as speech/language services, physical therapy and occupational therapy are provided within the general education class, rather than being offered as "pull-out" services. For example, speech therapists can help students with conversation skills in the context of reading instruction and occupational therapists provide can address personal care skills in the locker room after a physical education class.

In inclusive classrooms, individual student goals are addressed during general education activities and lessons. In this way, students with disabilities are not only able to practice important competencies and skills but may also master some or all of the general education objectives and standards. For instance, a

student who has a goal of learning how to use a calculator can practice this skill during a science lab while he may also be learning some of the elements of the periodic table.

Successful inclusive education can be supported by a number of factors:

- ✓ Administrators provide top-down leadership and expectations that children with special needs will be included and supported in regular classrooms;
- ✓ Children with special needs participate meaningfully in the curriculum, focusing on the same subjects and topics, but with adaptations where necessary (for example, adapted goals, materials, or teaching strategies);
- ✓ Children with special needs are educated alongside their peers, and are not segregated within the classroom;
- ✓ Children with special needs use the same facilities, environments, and spaces (for example, home rooms, lunch tables) as their typical peers where possible;
- ✓ Efforts at social engagement go beyond teaching "social skills" to children with special needs, by teaching typical peers how to be friends to children with special needs as they are, on their own – if different – terms, and by encouraging the development of safe and welcoming classroom communities;
- ✓ Children with special needs participate in extracurricular activities, and typical classmates are offered strategies to help support and include them;
- ✓ Teachers and paraprofessionals are trained in approaches to engage individuals with special needs, and strategies to adapt curriculum in accordance with their individualized goals;
- ✓ Special education and general education teachers spend time co-planning lessons, and when possible, co-teaching those lessons;
- ✓ All educators in the school take responsibility for all students. General education teachers take "ownership" and responsibility for their students with special needs, rather than fully delegating teaching to special education teachers or paraprofessionals.

The inclusive classroom

"The first time a general education teacher finds a student with an identified disability on his or her class list, he or she may feel unprepared to support the learner with such a label. I have often heard teachers say that they are 'not trained in special education' and, therefore, cannot be effective with students with disabilities. Although it can be beneficial to know about autism before teaching students with that label, teachers are most effective when they show acceptance, look for strengths in learners, provide personal attention when necessary, and allow for differences in the ways students approach tasks and complete classroom work." – *Paula Kluth, "You're Going to Love This Kid!"*[79]

Inclusive classrooms can include a wide range of supports to effectively address the individual needs of students on the autism spectrum:

Sensory supports: Consider the sensory needs and sensitivities of children with autism when planning the classroom environment. Many children with autism are disturbed by the flickering of fluorescent lights or simply find direct lighting too intense. For these students, it may help to use lamp lighting in some parts of the room or provide visors to those who can tolerate them. For those who struggle with sounds like noisy fans, hallway voices, bells, or fire alarms, headphones might be offered or seating away from the most disturbing sounds can be provided. Sensory toys or manipulatives (e.g. modeling clay, bean bags, novelty pens, desk-top fidgets) can provide more comfort for children who seek additional sensory input to regulate themselves. Similarly, they may be calmed by the ability to take short breaks within the classroom, with access to music through headphones and/or adapted seating (e.g., bean bags, rocking chairs, exercise balls).

Visual supports: Many learners on the spectrum are strong visual learners. Teachers can take advantage of this strength by using a range of visual strategies across the school day. Visuals can not only help teachers communicate more effectively with students, but can also provide real comfort to learners who may feel real anxiety when expectations, directions, or information is unclear. Some visuals commonly used in classrooms create predictability so that children know how long they will be expected to engage in a particular activity, and what will come next. Visual timers, picture schedules, and first/then boards all serve this purpose. Visuals can also be used to help students learn classroom requirements, stay on-task, and follow directions. Examples of these types of visuals include calendars, checklists, picture instructions, illustrated rules, and task cards. Finally, visuals can be used as communication tools. Photo albums, "I want" boards, and request cards are all examples of supports that can help learners with autism understand and be understood.

Communication supports: For many on the spectrum, communication struggles are at the heart of any learning, behavioral, or social challenges. Helping students improve communication skills and helping all learners successful connect with classmates should be priorities in inclusive classrooms. For students who are non-verbal or have unreliable communication, place communication at the center of all other goals. These students will need multiple opportunities across the school day to speak and share with others and/or to use their augmentative and alternative communication systems (e.g., sign language, letter boards, voice-output communication aids). Learners with complex communication needs will also require plenty of opportunities to interact with peers in the context of standards-based instruction. By using strategies such as stations and centers, peer tutoring, cooperative learning, classroom games, and reading partners, all students will have time to connect with peers and those needing practice with skills such as turn taking, asking and answering questions, and accessing new vocabulary or menus on their communication devices will have opportunities to learn academic content while gaining communication skills and competencies.

Keep in mind that addressing communication needs may be useful for all students on the spectrum. While students with more significant needs may need daily support to learn, be assessed, and to express themselves, other students may need help with pragmatics such as terminating a conversation, topic maintenance or interpreting facial expressions.

Adapting curriculum

"The presence of a student with significant disabilities often becomes the catalyst for teachers to examine critically instructional purpose, methods, and outcomes for *all* children. Educators are prompted to ask: What am I planning to teach, why is it important, and how can I provide instruction most effectively so that every learner benefits?" - *Alice Udvari-Solner*[80]

Curricular adaptations include adjustments and modifications that provide access to the general curriculum for diverse students. Adaptations can be further categorized as:

1) **Accommodations**: changes to provide equal access to curriculum and compensate for differing needs, without substantially changing the instructional level, content, or grading. These may include changes in seating, presentation, environment, materials, response format, time to complete tests, peer support for note-taking, and other considerations.

2) **Modifications**: changes to provide the student with meaningful and productive participation in the learning environment, but modified to reflect individual needs, abilities, and learning expectations. Modifications may focus instruction on a selected portion of the general content, provide additional supports such as calculators on math tests, visual hints or partially completed

problems, specific choices in place of open-ended questions, and may provide substitute projects in place of tests.

Several types of adaptations are frequently considered[81] before choosing a replacement curriculum:

1) **Input:** changes in the way instruction is delivered
2) **Output:** changes in how the student can respond or demonstrate knowledge
3) **Time:** changes in the time allowed for learning, completion, or testing
4) **Difficulty:** changes to the skill level, problems, or rules that must be followed
5) **Level of support:** changes in the amount of assistance by teachers, paraprofessionals, or peers
6) **Size:** changes in the number of items the student is expected to complete
7) **Degree of participation:** changes in the extent to which the student is actively involved
8) **Alternate goals:** changes in goals or expected outcomes while using the same materials

When children are included in general education classrooms, general and special education teachers often do not share a common language or planning process. The result is the continued use of traditional instructional methods that do not consider alternative approaches; overuse of "parallel" activities with special needs students that are unrelated to the content presented to typically developing peers and do not participate in the same activities; reliance on paraprofessionals or specialists to provide one-to-one assistance and adapt curriculum on-the-spot; and dependence on one individual to take responsibility of modifications and implementation.[82]

Udvari-Solner[83] studied *how* effective teachers think about and plan for the day-to-day participation of diverse students, and provides a well-defined process for developing curricular adaptations. The following steps describe this approach:

1) The educational team meets to ***identify the student's needs, strengths, goals, objectives, and expectations for participation*** in the general education setting.

2) Team members ***determine what to teach*** in specific curricular areas, themes, units of study, and instructional activities.

3) If the student would not be able to actively participate in the lesson without modifications and achieve the same learning outcomes as non-disabled peers, ***design appropriate adaptations***:
    a. Select specific learning outcomes
    b. Select the instructional arrangement, lesson format, and student-specific teaching strategies
    c. Engineer the physical and social environment
    d. Design modified materials
    e. Select natural support and supervision strategies
    f. Arrange alternative activities when initial adaptations are insufficient

4) ***Evaluate the effectiveness*** of the adaptations that are designed.

The central questions that teachers can ask themselves as part of this process are:

1) ***Can the student actively participate in the lesson without modifications and achieve the same essential outcomes?*** Examine which activities the student can participate in without significant adaptations to avoid overadapting or oversupporting the student.

2) ***Will student-specific learning outcomes need to be identified?*** Select and identify the student's individual education goals that will be integrated and emphasized within the general education activities. Curricular goals can be modified to:
    a. relate to the same content but be less complex
    b. have more functional applications
    c. alter performance standards
    d. adjust the pace of instruction or time requirements for completion
    e. adjust evaluation criteria
    f. individualize behavioral support

3) ***Can the student's participation be increased by changing the instructional arrangement?*** Options may include
    a. Large-group or whole-class instruction
    b. Teacher-directed small-group instruction
    c. Small-group learning
    d. One-to-one teacher-student instruction
    e. Independent seatwork
    f. Partner learning, peer tutors, or cross-age tutors
    g. Cooperative learning groups

4) ***Can the student's participation be increased by changing the lesson format?*** While lecture/demonstration/practice is the most commonly used lesson format, alternative formats can be chosen that make students more active participants in the learning process, including
    a. Thematic (centered or incorporating a particular theme, possibly one of great interest to the student with special needs)
    b. Activity-based (centered on an activity designed to demonstrate or clarify an area of content)
    c. Experiential (incorporating an event, field trip, or experience related to the teaching objective)
    d. Community-referenced (linking learning objectives to people, places, and things that the student encounters within her own community)

5) ***Can the student's participation and understanding be increased by changing the delivery of instruction or general educator's teaching style?*** As Udvari-Solner observes, "Appropriate student-specific teaching strategies go beyond the technical aspects of delivering instruction to include strategies to connect meaningfully the content of the lesson to the student's culture, home, and community life. It is only when the classroom teacher makes a conscious effort to teach and interact with a learner with disabilities that the child becomes a true member of the learning experience and the pattern of overreliance on supplementary instructional support from paraprofessionals or special educators can be lessened."

6) ***Can changes be made in the physical or social classroom environment that will facilitate participation?*** Adaptations to the physical environment may include noise level, lighting, furniture arrangement, accessibility of materials, and the intensity of visual or auditory input.

7) ***Will different instructional materials be needed to ensure participation?*** Changes in materials can allow a different mode of *input* to the student, or a different mode of *output* by the student. Changes in input may include the use of manipulatives and other materials that are activity-

based, visual, tangible, or related to a particular student's interests and personal context. Changes in output should assist the student in compensating for, circumventing, or replacing skills that may be challenging. These may include replacing written output with the use of pictures or poster boards, providing assistive and alternative communication technology, enhancing tests with visual choices, and similar approaches.

8) ***Will personal assistance be needed in the form of natural support and supervision to ensure participation?*** Natural supports are those that can be provided by the general education teacher and peers (who should initially be guided by showing how assistance should be provided, how the peer can be a good companion, and how the peer can provide information in a manner that is respectful and unobtrusive to the student receiving support).

9) ***Will an alternative activity need to be designed for the student and a small group of peers?*** Alternative activities can be designed when changes in the preceding instructional conditions are not sufficient. These activities should not represent parallel instruction (activities that are weakly or unrelated to the activities of the other students). Alternative activities are:
    a. Often activity-based or experiential or community-referenced;
    b. Similar or related to the curriculum of other students in the same class;
    c. Meaningful and age-appropriate for all students involved.

Finally, children with autism can often benefit from "priming" – previewing or pre-teaching portions of the curriculum, such as vocabulary or general concepts, before the subject is introduced in class. This strategy can result in fewer challenging behaviors and greater academic responding in children with autism who are included in general education classes.[84] Priming can also provide an opportunity to show the student how a given learning objective may be relevant to his or her own interests.

6: Accommodate Sensory and Movement Differences

"Accommodations are the personalized strategies that assist in temporarily overcoming differences in sensation and movement that are problematic to a person. Accommodations include the use of gesture, touch, rhythm, rituals, visualization, music, repetitive movements and other strategies to temporarily overcome difficulties starting, executing, stopping, combining and switching actions, postures, thoughts, speech, language and emotions. An accommodation assists the individual by activating mechanisms for control, regulation or change of movement. An accommodation may be performed alone by the individual with a sensory or movement difference or may involve another person; it may also include materials or equipment." – *Leary and Donnellan*[85]

One of the reasons for the differences in behavior among individuals with autism is that they often experience the world much differently through their senses than neurotypical individuals. They may also have difficulty affecting their world by initiating movement and speech.

Numerous self-reports from individuals with autism (see in particular Biklen[86] and Grandin[87]) describe these differences:

"All my thinking is visual. . . . My hearing is like having a hearing aid with the volume control stuck on 'super loud.' It is like an open microphone that picks up everything. . . .The nerve endings on my skin were supersensitive. Stimuli that were insignificant to most people were like Chinese water torture. . . . At various autism conferences, I have had 30 or 40 parents tell me that their autistic child seeks deep pressure stimuli." - *Temple Grandin*[88]

"To learn the technique of moving my right hand needed control over the ball and socket joint of the shoulder and then the hinge joint of my elbow and finally fold the other fingers and keep the point finger out. After that, focusing on the object which matched the word." - *Tito Mukhopadhyay*[89]

Sensory and movement differences are important because they affect how people with autism experience the world internally, they interfere with their ability to share thoughts and demonstrate competence, and also because many behaviors in autism emerge as strategies to *regulate* these sensory and movement differences.



Covering ears and avoiding eye contact are among the most obvious strategies, but individuals with autism also frequently develop elaborate rituals such as touching numerous points on a door frame, or stopping, swaying, or lining themselves up at specific points on the floor, as strategies to prepare themselves to move across certain barriers or spaces.

Some behaviors such as hand-flapping may have purposeful functions, such as containing excitement or providing sensory input. Before attempting to "manage" or eliminate these behaviors, be careful to consider the positive, adaptive function they may be providing for the individual with autism. If a behavior is clearly inappropriate, be sure to teach an alternative behavior or provide alternate forms of sensory input and support to allow the person to meet the same need in an appropriate way.

Understanding of these differences can provide a great deal of relief to people with autism, as well as improved behavior and learning outcomes. Each person with autism is different, so the best way to

identify sensory needs is through observation of that particular individual. The following are some common accommodations that may be helpful.

1) **Auditory:** headphones (preferably attractive and not stigmatizing) to regulate noisy environments; seating away from noisy equipment; providing directions in a soft voice; singing directions or instructional content; providing music breaks or subtle, non-stimulating background music; offering notice before classroom bells or fire alarms
2) **Visual:** reducing brightness or fluorescence of lighting; recognizing the use of peripheral vision rather than direct eye contact; providing visual learning adaptations such as pictures, visual schedules, and timers
3) **Proprioceptive:** deep pressure to large muscle groups (slow and only to an extent that is comfortable – without pinching or aggressive squeezing) particularly shoulders, upper arms, and large leg muscles, but NEVER around the torso or chest; weighted blankets or vests
4) **Vestibular:** swings, rocking chairs, spinning sit-toys or office chairs; gently rocking from side-to-side along with the person with autism during waiting times or transitions
5) **Tactile:** brushing skin with a soft therapy brush to increase tolerance; avoiding itchy or tight clothing; removing tags or other irritating objects from clothing; allowing shoes to be slipped on and off at appropriate times; limiting the use of strong detergents; attending to skin irritations particularly in dry winter conditions; use of hypoallergenic skin creams
6) **Homeostatic:** Maintaining a controlled range of temperature; maintaining regular sleep hygiene to reduce variations in circadian rhythm; awareness of changes in weather and barometric pressure (while weather does not appear to be significantly associated with behavior in autism in general,[90] changes in weather are associated with headache,[91] and weather-related behavioral changes are often reported by parents and teachers)

Praxis

Imagine reaching out, picking up a piece of food, and placing it in a bowl. Now imagine reaching out, picking up a piece of food, and placing it in your mouth. Though these sequences are largely the same, habitual sequences like this are typically not executed action-by-action. Rather, they are encoded as "action chains." In order to enable skilled and repeated execution, action chains are stored as separate motor plans in the parietal cortex (near the back of your head). The choice of which action chain to select at any point in time is generally made by the frontal cortex (near your forehead). In order to execute action chains, the brain relies on what is known as "frontal-parietal" connectivity, which is reported to be reduced in autism.[92]

Executing these action chains – praxis – relies on "ideation" of movements and sequences that conceptualize what to do, as well as motor planning and execution to carry them out.[93] [94] Based on physical and neurological evidence, difficulties in praxis appear to be a core feature of autism.[95] [96]

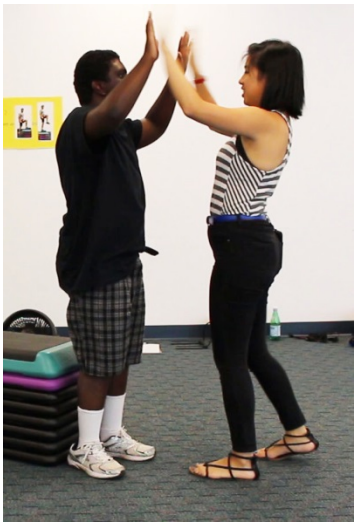
The gap between "ideation" of intended actions and their actual execution is clear in self-reports by individuals with autism:

"When I was growing up, speaking was so frustrating. I could see the words in my brain, but then I realized that making my mouth move [was needed to] get those letters to come alive, they died as soon as they were born. What made me feel angry was to know that I knew exactly what I was to say and my brain was retreating in defeat." - *Jamie Burke*[97]

"As far as being able to do things after they were shown to me ahead of time, I could not repeat an action simply by having seen it. I could make a picture of it in my head, but I could not put it physically

into motion. I could not [execute] my actions as I saw them in my mind, and consequently, I ended up withdrawing from actions." - *Alberto Frugone*[98]

"There are times when I can't do what I want to, or what I have to. It doesn't mean I don't want to do it. I just can't get it all together somehow. Even performing one straightforward task, I can't get started as smoothly as you can. Here's how I have to go about things: 1) I think about what I'm going to do. 2) I visualize how I'm going to do it. 3. I encourage myself to get going. . . .There are times when I can't act, even though I really, badly want to." – *Naoki Higashida*[99]



There is evidence to suggest that despite motor and sensory challenges in autism, the ability to process proprioceptive input (feedback from the joints and muscles to the brain) appears to be intact.[100] Individuals with autism may compensate for reduced long-range connectivity through increased reliance on proprioceptive input[101] (which is processed by somatosensory areas that neighbor the motor cortex). This ability to compensate encourages strategies that "play to the strengths" of individuals with autism.

Providing additional visual and proprioceptive feedback is an essential strategy that can help to bridge the gap between intention and action.

1) **Haptic feedback:** uses the sense of touch by applying mild backward pressure – *opposite* to the direction of movement – to provide proprioceptive feedback to the individual as they are learning to execute a new action. For example, when teaching a child how to type on a keypad, light backward resistance is provided to the palm of the child's hand as she reaches for the desired key. The objective is to push through this light resistance in a way that provides additional input. Haptic feedback has been reported to facilitate decoding of motor imagery, and "closing the sensorimotor loop."[102] This feedback is gradually reduced and eliminated as independent movement and initiation are achieved.
2) **Modeling:** In skills training for children with developmental delays, the passive observation of a model demonstrating the target skill is often more effective than hand-over-hand instruction.[103] With low-skilled students, peer-modeling – watching a relatively unskilled peer learning a motor skill – can be more effective than modeling by an instructor.[104]
3) **Passive touch:** Touch given prior to action affects the way that visual and proprioceptive information is integrated. The brain uses cues from passive touch and vision to update its own position[105] and better recognize its location and posture, and to produce reactions that improve stability.[106]

Self-reports from individuals with autism are consistent with these strategies:

"Touch is always a big help when an activity is new for me. Only through practice and through the gradual fading of touch the activity can be done independently. I needed to be touched on my right shoulder for doing any new skill. So I consider that the touch method is a vital step to speed up my learning skill." - *Tito Mukhopadhyay*[107]

I must picture actions before doing them. Picture = to visually represent them in my mind. It is efficacious for me to observe someone performing an action and then I can try to do it but with facilitation. It's necessary for me to gain real experience." - *Alberto Frugone*[108]

It is important to observe that hand-over-hand *guidance* is not the same as *feedback*. While guidance reduces execution errors, it significantly reduces the rate of learning, so performance degrades over the course of a few unassisted trials.[109] [110]For less-skilled individuals, *initial* guidance may be helpful, but once basic skill is obtained, guidance is counterproductive, and adapting the difficulty of the task accelerates motor learning.[111] [112] [113] Research on physical prompting suggests that a useful default strategy is to provide initial hand-over-hand guidance, fading gradually to less intrusive support that follows a brief (2 second) delay to encourage independence, while immediately correcting errors with hand-over-hand guidance if necessary.[114] Heavily guided practice is detrimental to learning, regardless of how frequently the practice occurs. With autism, guidance should emphasize the gradual withdrawal of direct input,[115] so that support is progressively faded in a way that encourages independence.

Getting stuck: automatic responses

When providing choices to individuals with autism, you may encounter situations where the person makes a choice and appears immediately unhappy when the requested choice is honored, or quickly asks to obtain the second choice as well. Self-reports from individuals with autism help to clarify why this may happen:

"I am able to say 'yes' or 'no' to questions if in fact they are not leading (i.e., do you need to go to the bathroom?). If someone asks me 'Do you want to go to the bathroom? Yes or no?' I will typically answer with a yes because it is the first word in the sentence that my autistic brain got stuck on. So what might appear not to be a leading question does functionally become a leading question if it triggers an automatic response. This by no means is a literal answer. My 'Yes' answer does not mean that I do not understand the question. . . . People with autism like routines, and if those routines are broken it does not mean that we don't understand what is happening it just means that it is harder for us than most to stop our brains from spinning off into their regular patterns. It is a process that is hard to understand and also hard to fully explain, but it can be terrifying to an autistic person not to be given repeated warnings when in fact their routine will change." - *Sue Rubin*[116]

"Security comes from making your choices heard. Choices, even something like selecting a cereal, could be hard. In the morning I was given many silly choices. But as my voice was not a true one, I had to pick the choice I heard. Many times it was not my true choice and both my mom and me were mad if I did not finish the cereal. I mean when you are little and you have speech that is only just a few small babyish words, you cannot get yourself unstuck to make a new selection. Like a car that keeps slipping into reverse gear because the track isn't strong enough to move forward. It was impossible to move to a joyful and delicious choice. After I was served, I was furious with myself and mad at mom. Even saying 'Do you want something else?' didn't help. The gears refused to move. I think many times it felt better to scream and run, than to feel like gagging on the bitter food. Even as the selections were viewed, my brain made only the same choice every day. Many times I desired pancakes but my lousy hand pointed to the bitter choice." - *Jamie Burke*[117]

"The reason people with autism repeat actions isn't simply because they enjoy what they're doing. The repetition doesn't come from our own free will . . . it's more like our brains keep sending out the same order, time and time again." – Naoki Higashida[118]

These experiences are consistent with evidence that individuals with autism may have difficulty mentally disengaging from an object or choice, even in situations where an alternate choice would be rewarding.[119] Burke observes the importance of developing "the ability to make things move along in order and not get stuck on an image or phrase that captured my attention." More research is needed to develop effective ways to improve initiation and reduce automatic responses in autism, but an

understanding of these challenges can be helpful simply by encouraging greater sensitivity to them. Though trial-and-error is often necessary, the following strategies may be helpful:

- ✓ provide regular opportunities to express choices
- ✓ vary the mode used to offer choices (verbally, using pictures, altering the number of choices)
- ✓ provide gentle verbal encouragement ("think about what you need", "try again")
- ✓ give the person time to pause before they move, make a choice, or engage in a task ("before you make a choice, think about which one you want to point to")
- ✓ create picture schedules and other visual tools (checklists, picture directions)
- ✓ find ways to say "yes" to more than one choice: "Yes. ___ today, and ___ tomorrow"
- ✓ recognize that offering a few minutes to fully complete a given activity (listening to a song, watching a video) can greatly improve the ability of a person with autism to transition to a new activity.
- ✓ provide haptic feedback, modeling, or passive touch to support initiation of movement
- ✓ play to strengths by enhancing visual and proprioceptive input when a person with autism is making choices or transitions

7: Build Relationships

"I have found in my experience that it is very hard for an autistic person to initiate relations with others. This does not mean that we do not desire communication. Instead our social rules are not socially acceptable. I have explained many times that my inability to look at someone when speaking to him or her does not mean I am avoiding the person as many presume. Sometimes, eye contact is literally painful for me to achieve. . . . Autism is not a polite disorder." - *Sue Rubin*[120]

One of the hopes of inclusive schools and communities is to help individuals with autism to build friendships and relationships. Unfortunately, simply placing a child with autism into an inclusive setting does not result in significant social interaction without additional support and instruction.[121] More importantly, attempts to improve the social *skills* of individuals with autism are unlikely to result in deeper social *relationships* unless typical peers are also taught how to engage individuals with autism as they are, and on their own terms. Ultimately, what matters for each person is genuine belonging.



Research is beginning to expand the definition of social behavior, emphasizing the importance of a framework based on social *relationships* rather than social skills.[122]

Friendship with a person with autism will generally appear "different" than other friendships, and no amount of social skills training is likely to remove those differences. Nor, in our view, should they.

Social skills training can be used to broaden the ability of people with autism to interact with others. They can be taught the sometimes arbitrary social conventions that they may need to navigate. In order to build relationships, however, these efforts should be complemented by helping *typical* peers to understand and accept others with autism, and to recognize that friendship with a person with autism need not resemble other relationships.

While it is difficult to make recommendations about something as complex as building relationships, we feel there are some considerations that can be helpful to anyone learning about autism and wanting to be as supportive and respectful as possible in interactions:

- ✓ Start by presuming the competence of the person with autism, recognizing that their ability to think may be much deeper than their ability to demonstrate thought.
- ✓ Remember that every person is an individual and that no two people and no two relationships will be the same.
- ✓ People with autism may yearn for friends and belonging, but may also be overwhelmed by "typical" social interaction. They also may not have learned to interpret subtle non-verbal cues or arbitrary social conventions that are part of ordinary relationships.
- ✓ Some people with autism may not have learned, or may not see the need for various "unwritten rules" involved in starting, ending and maintaining a back-and-forth flow of conversation. Be

aware that certain phrases or slang might also be taken literally. Help the person with autism to understand and develop useful conversation skills.

- ✓ Look for ways to connect on the person's terms. If the individual seems overwhelmed by busy environments, look for opportunities to connect in quiet places. If the person seems distressed when a lot of communication demands are placed on them, try activities that do not require communication or direct interactions (e.g., doing puzzles, walking silently, enjoying a movie).
- ✓ Speak to the person with autism in an age-appropriate way – be clear, but avoid utter simplicity or baby-talk. Hold up your end of the conversation even if the person with autism is not able to hold up theirs. Share, talk, disclose, confide, and inform as you would in any other relationship.
- ✓ In groups, acknowledge the presence of the person with autism and position them as part of the conversation to the extent they are comfortable, even if they can't speak. Use their name, acknowledge their behavior if you feel it is communicative (e.g., "Ken, you seemed to like that movie as much as I did!"), and provide opportunities for them to share a comment or idea.
- ✓ Be patient if the person needs longer pauses in the conversation to share an idea or initiate communication. Provide augmentative communication supports as needed.
- ✓ Acknowledge the interests of the person, when possible. Ask about the person's passions, hobbies, and fascinations. So often an individual's "obsessions" are dismissed or purposely ignored. Therefore, an opportunity to share favorite things with someone who is willing to listen and learn will likely be special and memorable.
- ✓ Learn about the person from the person. Ask if there are things you can do to support your friendship or relationship. Not every person can directly communicate suggestions, but some can do so. Others may be able to teach and offer hints through behaviors, vocalizations, and facial expressions.
- ✓ Remember that those on the spectrum are constantly being asked to learn new skills, try new things, and be on unfamiliar territory. Therefore, in starting and maintaining a new friendship, remember how much you can offer simply by being there or "showing up" for the person with autism.

Paula Kluth and Patrick Schwarz[123] illustrate the importance of accepting individuals with autism on their own terms, recognizing that friendship with a person with autism may appear quite different than friendships between neurotypical individuals:

"The notion that people relate in their own ways reminds us of Glory, a woman we have known for years. Glory has autism and is largely nonverbal. When we met her, we were told that her only 'hobby' was manhole covers and that she was not interested in people, only in objects. When Kathy, a caring neighbor, began working with her, however, that assumption was put to rest.

"Glory's favorite pastime was taking manhole–cover–walks through her neighborhood. Kathy would follow Glory as she weaved her way through the city blocks, located covers, and strolled around them leisurely. After a few weeks of engaging in the walks, Kathy not only found that she valued the quiet experience (as Glory tolerated no talking during this activity) but also began to see how social her new friend intended the experience to be. Glory always grinned widely when Kathy came over and scurried to put on her sandals. As the weeks went on, she began to walk closer and closer to Kathy and even began to point to interesting sights in the parks and throughout the neighborhood. Kathy found that Glory seemed to be using the walks to get not only much–desired peace and quiet in her life but also perhaps something even more valuable – the undivided attention of a friend."

8: Support Autonomy

It is often said that the easiest way to disable people with autism is to constantly do things for them that they are able to do for themselves. All of us appreciate help at certain points, and the reality of caring for an individual with autism is that sometimes time constraints require us to help "move things along." Still, individuals with autism are well-served if we support their autonomy and dignity by enabling them to take care of their day-to-day needs, develop *meaningful* work skills, and exercise choice over their own activities.

This section begins with a strong caveat: for many children and adults with autism, the pursuit of "functional skills" often takes priority over teaching communication. In other cases, as long as a child is able to communicate basic needs and wants, efforts to enrich communication, interaction, and literacy are abandoned or placed far behind these skills. Jamie Burke, a young adult with autism who learned to speak and type independently in his teens, offers a reminder to place communication first:

"So many things were hard for me to learn. I now think it was so foolish to ask me to learn to tie my shoes. My brain moved into hiding the reason for not being able to do it, but yet my school believed it important mostly as a way to tell you that you are now just greatly smart. Why is shoe tying important compared to the fact that you can't speak? Like saying the letters, mostly there was no pattern to follow in my brain for tying my shoelaces. After much practice, as with my words, it seemed a pattern moved into my brain, giving direction to my hands. I think my music therapy gave help with this. Doesn't tying your shoes mean you are now enclaved in the world of pigtails and basketballs? When a kid can't tie his shoes, you know they get frustrated with you, and even though those words of 'it doesn't matter' and 'we will use Velcro' are heard, your heart feels defeated. I screamed silently, 'Make my mouth work as my hands; can you idiots not see my struggle to tell you I have so many answers to the questions you place before my face? Isn't tying the speech to my mouth from my brain more critical to life than making a piece of cotton secure?' When I was 15 I tied my shoes and people rejoiced as if I had won an enormous prize in some battle . . . my mind believed this excited reaction to tying my shoes still foolish."

- *Jamie Burke*[124]

Many day-to-day skills are certainly important, particularly self-care. But efforts to teach various "functional skills" should augment, not replace, efforts to improve communication, broaden social relationships, support inclusion, and enhance the quality-of-life of people with autism.

Task analysis

Task analysis is a widely used approach to teach a variety of skills to individuals with autism. It involves breaking down a complex skill into a series of less challenging components, and then linking those components together in one of two ways:

1) **Forward chaining:** Start by teaching the first step of the skill, and then complete the remainder of the task for the person. Gradually teach additional steps as each one is mastered, until the person is able to complete the skill from beginning to end without assistance.
2) **Backward chaining:** Teach the very last step needed to complete the task. Complete the task up to that last step, and then prompt the person to complete the last step independently. Gradually teach the second-to-last step and so on, as each one is mastered, until the person is able to complete the entire skill from beginning to end without assistance.

When choosing what level of support to provide, several options are available:

1) **Most-to-least prompting (MTL)**: The teacher provides hand-over-hand guidance through the initial teaching, followed by gradually less intrusive prompting such as support at the wrist, then the upper arm, then the shoulder, then light touch, as the skill is developed.
2) **Most-to-least with time delay (MTLD)**: Begins with hand-over-hand guidance followed by less intrusive prompting as the skill is developed, but before offering the less intrusive prompts, a time delay (e.g. 2 seconds) is provided to encourage independence. Any errors are immediately corrected by providing hand-over-hand assistance if necessary.
3) **Least-to-most prompting (LTM)**: The person is given a brief opportunity to perform the action (often with a verbal prompt or an expectant look), followed by the least intrusive prompt that is needed. Gradually more intrusive prompting is provided if necessary.

For individuals with autism, the following guidelines have been recommended as best practice:[125]

- MTLD appears to be the best default strategy when an individual's learning history is unknown.
- MTL or MTLD is preferred if errors tend to increase problem behavior or create other learning difficulties. Among these choices, MTL minimizes errors but may slow the acquisition of the skill.
- LTM appears preferable if students have a history of rapidly learning skills with this method.
- Frequent progress monitoring is advised to ensure that errors do not interfere with learning.

Choices

People with autism often experience a great deal of external control from others, without the ability to exercise the same choices that typical individuals ordinarily make. In many cases, oversight is necessary to protect against harm to the person with autism or others. Unfortunately, this oversight is often accompanied by living conditions, controls, and restricted choices that most of us would find intolerable.

It may be helpful to ask the question: "What choices would a typical individual be able to exercise in this same situation?" Then ask: "What oversight is truly necessary in order to prevent harm to this person or others?" Consider whether providing a given choice will create an ongoing expectation for the same opportunity. If so, rather than restricting the option altogether, it may be possible to create a visual schedule or other support (e.g. red light / green light) to increase predictability about when the desired object or activity will be available.

Offering choices reduces behavioral problems, and increases motivation in educational settings and in daily living. Compared with no-choice environments, both the ability to choose between activities (e.g. working on math versus English, listening to music versus playing a game) and the ability to choose within activities (using a pen versus a pencil, choosing where to sit) encourage less challenging behavior and fewer escape attempts. Not surprisingly, the ability to choose between activities is particularly effective.[126] Most importantly, providing the ability to exercise freedom of choice is more than a behavioral strategy. It is a human right that supports autonomy and personal dignity.

Toileting

Families with a child on the autism spectrum often spend a great deal of time assisting with toileting, and preventative measures such as diapers can remain in use far longer than is ordinarily the case with neurotypical individuals. The quickest and most effective way to complete potty training is to go "cold turkey" from diapers and pull-ups, even at night. While these items can reduce the frustration of accidents, they tend to reduce the motivation to achieve independence, and mute the consequences of accidents. Begin by obtaining several packs of underwear (you will need them) and a mattress cover.

Toileting is much like any other behavior. The goal is to understand the triggers or signs of need, provide a way to communicate that need, consistently reinforce successful behavior, minimize attention or reinforcement in the event of accidents, and fade positive reinforcement only after sustained success.

The following approach is adapted from Koegel:[127]

For at least the first week, maintain data on attempts, successes and accidents. This is extremely useful in helping to predict when an accident is likely, and will allow you to increase the frequency of toileting attempts around that time. It can also be helpful to observe the child's behavior just before a bowel movement. The child may lean over, go to a corner of the room, or give other cues.

1) **Every 15 minutes - Dry pants check:** Go to the child and place his/her hands over the front of his/her pants. Give verbal reinforcement if the child is dry. Be sure to actually use the word "dry" (e.g. Great job! Your pants are dry!).
2) **Every 30 minutes – Attempt to toilet:** The idea here is to teach the child to independently communicate the need to use the potty.
    a. Ask the child "Do you want to go to the potty?" (again, be sure to actually use the word "potty")
    b. If the child is verbal, prompt for the verbal response "Go potty"
    c. If the child is not verbal, have the child hand you a picture card for "Potty"
    d. Undress the child with minimal prompts. Sit on the potty for 30-60 seconds. Give lots of verbal reinforcement. "Good trying!!"
3) **If there is an accident: Practice 2-3 times.** This not only provides a brief but non-punishing consequence for the undesirable behavior, but also provides an opportunity to model the desirable behavior.
    a. Be very matter-of-fact. Don't express anger or disappointment. As with other behavioral approaches, it is important to limit the attention given to undesirable behavior or outcomes. If the child is wet, place the child's hands over his pants and say "Uh oh. Your pants are wet". Then walk over to the potty as if you are doing a regular attempt. Say: "We want to go _____ in the potty."
    b. Practice 2-3 times: Put child on potty for several seconds, then off, with only mild reinforcement, "That's good, one more time." Remember to be very matter-of-fact. Otherwise, if the child enjoys attention, you may inadvertently reinforce the child to have more accidents rather than fewer.
4) **If there is a success, throw an immediate "party!"** As with other behavioral approaches, it is important to provide strong reinforcement for positive behavior. Clap, verbally reinforce the child, give big smiles, toy reinforcers, special treats, anything that will convey major success to the child. Be sure that this reinforcement is immediate and enthusiastic.

Example Data:

Time	Attempted	Accident (U/BM)	Success (U/BM)
10:30	X		
11:00	BM		
11:30	X		
12:00			U (!)

U urine, BM bowel movement

- Be consistent.
- Expect accidents and occasional frustration, particularly when you just miss a bowel movement.
- Focus on reinforcement of successes and matter-of-fact approach to accidents.
- Remember to get the child involved in initiating, either by using the word “potty” or a picture card.
- You may see initial success after a week or so, and probably within a few weeks, but expect at least an occasional accident for a few months.

Sleep

Sleep disruptions occur in as many as two-thirds of children with autism. These problems can include delayed onset of sleep, night-time waking, early-morning wakening, and dependence on external support such as co-sleeping with parents. Because the sleep-wake cycle is affected not only by the light-dark cycle but also by day-to-day activity and social cues that may be altered or limited in autism, it has been suggested that children with autism may have greater difficulty entraining a normal sleep cycle.[128]

The first-line approach to sleep problems is to develop good habits that contribute to a regular sleep cycle.

- ✓ Encourage regular exercise and activity during the day.
- ✓ Enrich the day with social interactions and attention, particularly where sleep disturbances have an attention-seeking aspect.
- ✓ Decide on a sleep schedule with a regular bedtime and waking time, avoiding wide day-to-day variations.
- ✓ Provide predictable advance cues that bedtime is coming.
- ✓ Establish a regular bedtime routine (brushing teeth, washing face, dressing for bed, reading a story). Include activities that provide attention, but avoid television, games, or exercise before bed.
- ✓ When finally in bed, avoid over-reliance on sleep “aids” such as bottles, music, television or other assistance that will not be available if the person wakes in the middle of the night.
- ✓ Help to entrain the sleep cycle using the light-dark cycle: open drapes and turn on lights in the morning (possibly in a slightly graduated way); dim lights somewhat during the bedtime routine. Bright light reduces the secretion of melatonin that the body naturally produces to induce sleep.
- ✓ Ensure that the environment is supportive of sleep by limiting outside noises and variations in bedroom temperature.

When sleep problems persist despite supportive sleep habits, there are two strategies of choice: graduated extinction, and rescheduling the sleep-wake cycle. The procedures that follow are adapted from Durand (2011)[129] and Weiskop, Richdale, and Matthews (2005).[130] See also Mindell et al (2006)[131] for a useful review of evidence supporting the effectiveness of these procedures.

Graduated extinction is a useful strategy if the child is disruptive after bedtime. If the child is not disruptive, efforts should focus on rescheduling the sleep-wake cycle.

Begin by keeping a sleep diary to enable you to recognize patterns. Note the time that the bedtime ritual (wash face, brush teeth, read story) begins, lights out, the estimated time of sleep onset, waking time, and any intervening behaviors such as crying, night waking, or co-sleeping with parents or siblings.

Graduated extinction

Effective behavioral responses to challenging behavior combine extinction – the removal of positive reinforcement for the difficult behavior – with support and reward for more efficient alternate behaviors that allow the same need to be met. Among behavioral approaches to improve sleep in individuals with autism, a review by Schrek (2001) concluded that extinction has the most well-established evidence of efficacy.[132]

Graduated extinction involves gradually removing the reward for crying and protests at bedtime by progressively increasing the amount of time that these protests are ignored, while still allowing the parent to periodically check on the child. During the day, the child should receive plenty of attention, emotional engagement and activity, but after the child has gone to bed, it is not in the child's interests (or the family's interests) to reinforce behaviors that prevent the child from falling asleep on his own.

As with all behavioral strategies, examine the antecedents and reinforcements that surround the behavior itself. In children where night waking is a problem, Weiskop, Richdale, and Matthews report that the child has typically learned to fall asleep with a specific stimulus (e.g. a bottle of milk, the mother's presence, being on the couch), and after waking in the middle of the night, the child becomes dependent on re-establishing the same conditions in order to resume sleep. Children also may engage in disruptive behavior because of lack of cues that bedtime is approaching. In some cases, bedtime is set too early, or naps are provided so frequently or close to bedtime that the natural stimulus for falling asleep – tiredness – is not present at bedtime. Challenging sleep behaviors are often positively reinforced by parent efforts to prevent or terminate those behaviors (e.g. providing attention, allowing the child to co-sleep, allowing the child to fall asleep outside the bed).

How to proceed:

1) Create a regular bedtime routine that takes about 30 minutes. Include the opportunity to potty and have a drink so that these needs do not become excuses to interrupt sleep. If the routine allows the child to ask for "one more ___" (story, drink, minute), that is fine as long as you are firm in denying any additional requests.
2) Set an agreed-on bedtime that will not change over the course of the plan. Explain the rules to the child initially, but not in response to behaviors after bedtime.
3) Decide on the amount of time you will wait before going in to check on the child, generally 3-5 minutes for the first night.
4) Choose a night to begin the plan. Expect that the first night will be difficult and without much sleep. Try to include plenty of attention during the day, and during the bedtime routine. This will not only help the sleep cycle, but will also help to reduce feelings of guilt during the extinction process.
5) After the bedtime routine, put the child to bed at the chosen time, leave the room, and WAIT the agreed upon amount of time (3-5 minutes) before going in to check on the child.
6) After waiting the full amount of time, if the child is still crying, go into the bedroom, gently tell the child matter-of-factly to go to sleep, and leave. You do not have to be cold, but do not pick the child up, cuddle, yell, spend time tucking the child in, offer drinks, or engage in conversation or repeated explanations of the rules.
7) If the child comes out of the bedroom, be very matter-of-fact and immediately take the child back to bed. Again, avoid reinforcing the behavior with positive or negative attention.

8) Wait the same amount of time (e.g. 3-5 minutes) before going back into the room again. Continue this process with the same amount of time until the child is asleep. You may, but do not need to, wait an increasing amount of time between visits.
9) Every night, extend the planned "extinction" time by an additional 2-3 minutes.
10) Reinforce the child in the morning for success (or reasonable success).

While ordinary comfort items such as teddy bears may be allowed, the child should be expected to fall asleep without the presence of a parent or a bottle. Keep in mind that the most effective behavioral approaches couple extinction of negative behaviors with positive reinforcement and environmental enrichment that allow the same needs to be met more efficiently than with negative behavior. For this reason, be sure that the child enjoys activity and attention during the day. The same approach is encouraged as a strategy to replace specific behaviors. For example, for children who rock back-and-forth in bed at night, it may be useful to provide greater vestibular stimulation (e.g. swings, rocking) during the day. Stop the extinction process if the child is sick or in danger, in order to address these more immediate needs.

Rescheduling the sleep-wake cycle

Two methods are typically used to help "reset" the sleep-wake cycle.

Sleep restriction involves reducing the time that the child sleeps, so that the child is tired when she is put to bed and can fall asleep easier. Once a normal sleep cycle is restored, bedtime is gradually moved to the desired time. Sleep restriction often initially requires the parent to stay up much later than usual, as well as efforts to keep the child from falling asleep before the later bedtime.

How to proceed:

1) Create a bedtime routine that is only 10-15 minutes, as the child may be very tired at the chosen bedtime.
2) Use the sleep diary to identify the time that the child tends to fall asleep if left alone, then add 30 minutes to this time. This is the target bedtime (and may be quite late initially).
3) Select the time to wake the child that, when combined with the new bedtime would allow the child to get 90% of the sleep the child normally gets.
4) Keep the child awake before the target bedtime even if she wants to go to sleep. Do not allow more naps during the day.
5) If the child does not fall asleep within 15 minutes of the target bedtime, take the child out of the bedroom and extend the bedtime for one more hour.
6) If the child falls asleep within 15 minutes of the target bedtime without resistance for two consecutive nights, move the target bedtime 15 minutes earlier.
7) Continue to move the bedtime earlier until the desired bedtime is reached.

Scheduled awakening is used in night-waking situations when a child wakes or experiences nightmares in the middle of the night. The process involves *gently but not fully* awakening the child a short period of *time* before they would typically wake during the night. Durand notes "the reason why scheduled awakening is effective is not currently understood but may involve 'reprogramming' the sleep cycle to a more regular-sleep-wake schedule. It also may give your child experience falling asleep alone when drowsy."

How to proceed:

1) Use the sleep diary to identify the earliest time that the child typically awakens during the night, the scheduled awakening time will be 30 minutes *earlier* than this time.

2) On the first night, wake the child gently but not fully by touching or talking to him until he opens his eyes. Then let him fall back asleep.
3) If the child awakens very easily on the first night, move the scheduled awakening time an additional 15 minutes earlier on the next night, and maintain that same scheduled awakening time on all subsequent nights.
4) Repeat the process until the child goes a full week without a night waking or nightmare. Then skip the scheduled awakening on one night during the next week. If night waking or nightmares recur, go back to waking the child every night until there is a full week of success. Then gradually reduce the number of nights with scheduled awakenings until the process is no longer required.

Durand notes that for all of these interventions, "you may find an initial increase in episodes of sleepwalking, sleeptalking, or sleep terrors. These are non-dream related problems that sometimes occur when someone is not getting enough sleep. Sleep terrors are especially troublesome for families because the child experiencing this problem is so upset (e.g. screaming, sweaty), but is really not awake. Attempting to awaken a child from a sleep terror is difficult but not dangerous as some think. The good news is that the child will have no memory of this in the morning. Try to be patient with these changes, and try to take note of how often they happen. Our experience is that they decrease as a child's sleep improves."[133]

Changes in the body's normal melatonin rhythm may contribute to sleep problems in autism. While behavioral approaches are encouraged as a long-term strategy, melatonin and controlled-release melatonin have been shown in controlled trials to improve sleep problems in children with autism. A few studies have reported occasional side effects such as tiredness/grogginess, dizziness, and headache that were immediately eliminated after discontinuing melatonin use. Ordinary (fast release) melatonin was found to be most effective when initially inducing sleep was the primary concern, while controlled-release formulations were more useful for sleep maintenance.[134] Medication is not advisable as a long-term solution, and a physician should be consulted before introducing melatonin or other medications or supplements.

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